

**PERCEPTIONS OF THE RELATIVES OF PATIENTS
SUFFERING FROM CHRONIC RENAL FAILURE REGARDING
KIDNEY DONATION**

by

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submitted in accordance with the requirements
for the degree of

MASTER OF ARTS

in the subject

HEALTH STUDIES

at the

UNIVERSITY OF SOUTH AFRICA

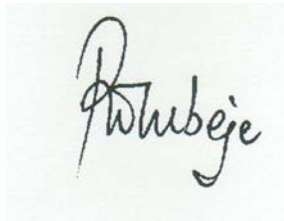
SUPERVISOR: PROF MM MOLEKI

JUNE 2013

Student number: 33222630

DECLARATION

I declare that **PERCEPTIONS OF RELATIVES OF PATIENTS SUFFERING FROM CHRONIC RENAL FAILURE ABOUT KIDNEY DONATION** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

A handwritten signature in black ink, appearing to read 'P. Ntombithini Mbeje', is shown on a light-colored background.

Full names

PRETTY NTOMBITHINI MBEJE

28 February 2013

Date

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ABSTRACT

This study aimed at exploring and describing the perceptions of relatives of patients with chronic renal failure regarding kidney donation.

The number of patients suffering from chronic renal failure awaiting kidney transplantation is on the increase, while the treatment they get in the interim is not cost effective. The researcher used qualitative descriptive and exploratory research using the Potter and Perry's Health Belief Model. She applied purposive sampling and used semi structured interviews to collect data from 45 participants who were all relatives of patients coming for haemodialysis at a selected hospital in KwaZulu-Natal.

Data analysis identified participants' perceptions regarding chronic renal failure and kidney donation. Findings of the study revealed that most relatives were fully aware of kidney donation, but fear and lack of knowledge regarding kidney transplantation were the main barriers to them offering themselves for kidney donation.

The researcher recommends that the Renal Transplant Multidisciplinary Committee should ensure the public is informed about kidney donation and more intensive education should be given to the relatives of patients suffering from chronic renal failure at an early stage in the illness to give them more time to come to terms with the concept of kidney donation.

KEY CONCEPTS

Perceptions, relatives, chronic renal failure, kidney donation, kidney transplant, haemodialysis, renal multidisciplinary health committee.

ACKNOWLEDGEMENTS

I would like to thank the following persons for their respective contributions to this dissertation:

- My husband, Nhlanhla Mbeje, for his unconditional love, support and encouragement
- My three children, Luyanda, Lungelo and Phumla, for their support and understanding
- A special thanks to my retired supervisor, Dr MC Kriel, for her support and guidance and Dr MM Moleki, who has helped me throughout this study
- The fellow relatives of patients suffering from chronic renal failure in Addington Haemodialysis Unit of Addington Hospital
- The ex-acting CEO of Addington Hospital, Dr R Mokoena, Nurse Manager, Mrs Chinniah and the Operational Unit manager of Haemodialysis Unit, Sr M Green
- The KwaZulu-Natal Department of Health, for giving me permission to conduct the study
- Prof AG Assounga, an expert analyst, for guiding me in analysing my data, despite his busy schedule
- Special thanks also go to my editor, Mrs M Addis as well as Mrs R Coetzer for finalising the whole dissertation.

Dedication

I dedicate this work to my late dad, Mr PD Magenuka.

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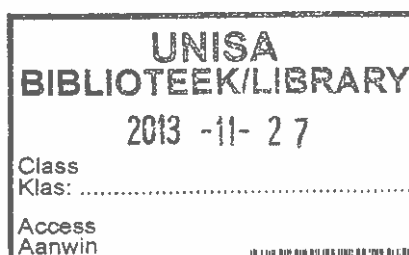


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Table of Contents

CHAPTER 1	1
ORIENTATION TO THE STUDY	1
1.1 INTRODUCTION.....	1
1.2 BACKGROUND TO THE RESEARCH PROBLEM.....	1
1.2.1 End-stage renal failure	2
1.2.2 Financial implications for renal transplantation in the Republic of South Africa.....	2
1.3 PROBLEM STATEMENT	3
1.4 RESEARCH PURPOSE	4
1.5 RESEARCH OBJECTIVES	4
1.6 THEORETICAL FRAMEWORK.....	4
1.6.1 Assumptions underlying the study	5
1.7 DEFINITION OF KEY CONCEPTS	6
1.7.1 Perceptions	6
1.7.2 Chronic renal failure	6
1.7.3 Kidney donation	6
1.7.4 Patient.....	7
1.7.5 Relatives	7
1.7.6 Suffering.....	7
1.8 RESEARCH DESIGN AND METHOD	8
1.8.1 Research design	8
1.8.2 Research setting	8
1.8.2.1 Population	8
1.8.2.2 Criteria for inclusion	9
1.8.3 Sampling approach and technique	9
1.8.4 Sample.....	10
1.8.5 Data collection approach and method	10
1.8.6 Data collection.....	11

1.8.7	Data analysis	12
1.9	ETHICAL CONSIDERATIONS	13
1.9.1	Protecting the rights of the participants	13
1.9.1.1	Autonomy and informed consent.....	13
1.9.1.2	Justice.....	14
1.9.1.5	Respect.....	15
1.9.1.6	Beneficence and non-maleficence.....	16
1.9.2	Protecting the rights of the institution.....	17
1.9.3	Scientific integrity of the research.....	17
1.10	SIGNIFICANCE OF THE STUDY.....	18
1.11	SCOPE AND LIMITATIONS OF THE STUDY	18
1.12	STRUCTURE OF THE DISSERTATION	18
1.13	CONCLUSION	19
CHAPTER 2	20
LITERATURE REVIEW	20
2.1	INTRODUCTION.....	20
2.2	CHRONIC RENAL FAILURE.....	20
2.2.1	Definition of chronic renal failure	20
2.2.2	Impact of chronic renal failure on family members and public health	21
2.2.3	Brief causes of chronic renal failure.....	22
2.2.4	Global prevalence and incidence of chronic renal failure	22
2.2.5	Stages of chronic renal failure	24
2.2.6	Treatment options for chronic renal failure	25
2.3	HAEMODIALYSIS.....	25
2.3.1	Definition of haemodialysis.....	25
2.3.2	Description of haemodialysis.....	25
2.3.3	Objectives of haemodialysis	26
2.3.4	Types of accesses used for haemodialysis	26
2.3.5	Incidence of haemodialysis	26
2.3.6	Effects on the patient.....	27

2.4	PERITONEAL DIALYSIS	28
2.4.1	Definition of peritoneal dialysis	28
2.4.2	Description of peritoneal dialysis	28
2.4.3	Objectives of peritoneal dialysis	28
2.4.4	Access used for peritoneal dialysis.....	29
2.4.5	Incidence of peritoneal dialysis.....	29
2.4.6	Effects on patients.....	29
2.5	KIDNEY TRANSPLANTATION AS A VIABLE TREATMENT OPTION	30
2.5.1	Definitions of related concepts	30
2.5.1.1	Kidney	30
2.5.1.2	Donation.....	30
2.5.1.3	Kidney donation	30
2.5.2	The legal aspects of kidney donation	30
2.5.3	Living donor transplantation	31
2.5.3.1	The recipient	31
2.5.3.2	The donor.....	32
2.5.3.3	The role of the Kidney Transplantation Multidisciplinary Committee	32
2.5.4	Cadaver donor versus living donor	34
2.5.5	Transplantation versus dialysis	35
2.6	THE HEALTH BELIEF MODEL	37
2.7	PERCEPTIONS TOWARDS KIDNEY DONATION.....	39
2.9	CONCLUSION	40
	CHAPTER 3.....	41
	RESEARCH DESIGN AND METHOD.....	41
3.1	INTRODUCTION.....	41
3.2	RESEARCH SETTING.....	41
3.3	RESEARCH DESIGN.....	42
3.3.1	Qualitative design.....	42
3.3.2	Exploratory design	44
3.3.3	Descriptive design.....	44

3.4	RESEARCH METHOD.....	44
3.4.1	Population and sampling	44
3.4.2	Eligibility criteria	45
3.4.3	Exclusion criteria	46
3.4.4	Sample.....	46
3.5	DATA COLLECTION.....	47
3.5.1	Development of the data collection instrument	48
3.5.2	Data collection process	50
3.6	DATA ANALYSIS	51
3.7	TRUSTWORTHINESS OF THE STUDY	54
3.7.1	Credibility	54
3.7.2	Transferability	55
3.7.3	Dependability	55
3.7.4	Confirmability	55
3.8	CONCLUSION	55
	CHAPTER 4.....	56
	ANALYSIS, PRESENTATION AND DESCRIPTION OF RESEARCH FINDINGS	56
4.1	INTRODUCTION.....	56
4.2	SAMPLE CHARACTERISTICS	56
4.3	DATA MANAGEMENT AND ANALYSIS	57
4.3.1	Data management.....	57
4.3.2	Data analysis	58
4.4	RESEARCH RESULTS.....	60
4.4.1	Theme 1: Participants' basic knowledge of understanding of chronic renal failure	60
4.4.1.1	Sub-category 1: Chronic renal failure is when the kidneys fail to function normally resulting in inability to pass urine	61
4.4.1.2	Sub-category 2: Chronic renal failure is the disease that affects the kidneys.....	61
4.4.1.3	Sub-category 3: Chronic renal failure is when the body depends on haemodialysis in order to survive	61

4.4.2	Theme 2: Participants' awareness of the consequences of missing haemo-dialysis sessions	62
4.4.2.1	Sub-category 1: Patients who miss their haemodialysis treatment experience difficulty in breathing	62
4.4.2.2	Sub-category 2: Patients cannot miss any sessions as the haemo-dialysis unit is closed after hours	63
4.4.3	Theme 3: Participants' awareness of kidney donation	63
4.4.3.1	Sub-category 1: Relatives had heard about kidney donation from the patients, the renal team and the media.....	64
4.4.4	Theme 4: Participants' views/perceptions about kidney donation	64
4.4.4.1	Sub-category 1: Pre-existing medical conditions decrease the chances of getting donors	65
4.4.4.2	Sub-category 2: Fear of surviving with one kidney	66
4.4.4.3	Sub-category 3: Participants failing some investigation for donor work-up and thereby not continuing with the preparation for kidney donation	66
4.4.5	Theme 5: Participants' religious influence on kidney donation.....	67
4.4.5.1	Sub-category 1: Some religious denominations accept kidney donation	68
4.4.5.2	Sub-category 2: Some participants are not aware of any religious influence in kidney donation.....	69
4.4.5.3	Sub-category 3: Any organ donation is religiously taken as "the gift of life"	69
4.4.5.4	Sub-category 4: Islamic religion views kidney donation as the means of alleviating pain and saving life.....	69
4.4.5.5	Sub-category 5: Participants' fear of not being accepted by the ancestors if not buried as "whole".....	70
4.4.6	Theme 6: Participants' Initial health services sought by the patient	70
4.4.6.1	Sub-category 1: Family doctor or local clinic followed by referral to hospital.....	71
4.4.6.2	Sub-category 2: Initial use of home remedies followed by seeking professional advice	71
4.4.6.3	Sub-category 3: Initial use of herbal medication given by witchdoctors, followed by seeking professional advice.....	72
4.5	OVERVIEW OF RESEARCH FINDINGS	72
4.6	CONCLUSION	73

CHAPTER 5	74
CONCLUSIONS AND RECOMMENDATIONS	74
5.1 INTRODUCTION	74
5.3 RECOMMENDATIONS	77
5.3.1 Department of Health	77
5.3.2 Nursing management	78
5.3.3 Further research	78
5.3.4 Contribution of the study	78
5.4 LIMITATIONS OF THE STUDY	79
5.5 CONCLUDING REMARKS	79
LIST OF REFERENCES	81

List of tables

Table 2.1	Stages of chronic renal failure in relation to glomerular filtration rate.....	23
Table 4.1	Participants' basic knowledge of understanding of chronic renal failure	60
Table 4.2	Participants' awareness of the consequences of missing haemodialysis sessions .	62
Table 4.3	Participants' awareness of kidney donation.....	63
Table 4.4	Participants' views/perceptions about kidney donation	65
Table 4.5	Participants' religious influence on kidney donation.....	68
Table 4.6	Participants' initial health services sought by the patient	71

List of figures

Figure 2.1	Health Belief Model	38
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List of annexures

Annexure A Clearance certificate from the University of South Africa, Health Studies Research and Ethics Committee

Annexure B Questionnaire for data collection

Annexure C Letter requesting permission to conduct research

Annexure D Letters granting permission to conduct research

Annexure E Informed consent form

Annexure F Editor's declaration

CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Limited knowledge and understanding of the perceptions of people usually lead to stereotyping, discrimination, prejudices, racism and biases. Increasingly, health is influenced by social and economic circumstances. A growing body of literature has demonstrated that although renal replacement therapy for patients with chronic renal failure is cost effective, this disease continues to impact on health-related quality of life. White, Chadban, Jan, Chapman and Cass (2008:229) state that “the global burden of end-stage renal failure is concealed behind the statistics which reflect only the number of people treated, not those who die of kidney failure or cardiovascular complications. The number of patients with chronic renal failure awaiting kidney transplantation is drastically increasing and living donor kidney transplantation is the treatment of choice and has economic and quality-of-life advantages”. In this study, the researcher intends to explore and describe the perceptions of the relatives of patients suffering from chronic renal failure regarding kidney donation.

According to Farhenwald and Stabnow (2005:347), the traditional belief about the body having to remain intact to enter the spirit world has been cited as a barrier to the concept of kidney donation. In addition, the potential conflict between an individual's intent to donate and their family's difficulty with honoring that request as a result of their personal beliefs is apparent. The issue of beliefs has a great impact on kidney donation and cannot be ignored and therefore the transplant coordinators need to be sensitive and congruent.

1.2 BACKGROUND TO THE RESEARCH PROBLEM

Chronic kidney disease is increasingly being recognised as a global public health problem. World Kidney Day, which was initiated in March 2006, to be observed annually, sends a clear message to the public, government health officials, physicians,

allied health professionals, patients and families that chronic kidney disease is common, harmful, and treatable. According to White et al (2008:229), the recognition of chronic kidney disease as a public health problem has evolved, in part, from the acceptance of the conceptual model, definition, and classification of chronic kidney disease or chronic renal failure proposed by the National Kidney Foundation Kidney Disease Outcome Quality Initiative in 2002 and modified by Kidney Disease Improving Global Outcomes in 2004. Because of the dearth of national registries and representative surveys, estimating the burden of end-stage renal disease in low and middle income countries is difficult.

Insufficient organ donor and transplant programmes, the health system, financing issues, ethical regulation of transplantation and the cost of pharmaceuticals commonly pose additional barriers to the delivery of efficient and cost-effective renal replacement therapy (White et al 2008:229). At this point, it is clear that dialysis and transplant programmes are dependent on the availability of funding and donors.

1.2.1 End-stage renal failure

According to Kasper, Braunwald, Fauci, Hauser, Longo and Jameson (2005:1665), chronic renal failure is a pathophysiologic process with multiple etiologies, resulting in an inexorable attrition of nephron number and function and frequently leading to end-stage renal disease or end-stage renal failure. In turn, end-stage renal failure represents a clinical state or condition in which there has been an irreversible loss of endogenous renal function, of a degree sufficient to render the patient permanently dependent upon renal replacement therapy (dialysis or transplantation) in order to avoid life-threatening uraemia. Kasper et al (2005:1665) further argue that a definition of chronic renal failure requires that a pathophysiologic process lasts more than three months.

1.2.2 Financial implications for renal transplantation in the Republic of South Africa

Because of financial constraints, the National Health Department of South Africa, in consultation with the nephrologists, has formalised a protocol for the management of end-stage renal failure. The state facilities will offer renal replacement therapy only to patients who are eligible for a transplant (Naicker 2003:121).

There are no constraints for gender, race or social status. Dialysis is offered to transplantable patients who are able to attend the treatment. Transplantation of organs from living unrelated donors requires permission from the Minister of Health (Naicker 2003:121). The trade in organs is forbidden by law in most countries in Africa.

There are two types of treatment available to patients with kidney failure which alleviates the condition and these are kidney transplants and dialysis (haemodialysis or peritoneal dialysis). However, having worked in the Renal Department for several years, the researcher has seen that only those with good socio-economic status can afford renal therapy. Each haemodialysis machine costs R100 000.00 and haemodialysis costs R700.00 per session. Therefore, if a patient dialyses three times a week, it costs over R100 800.00 per annum, excluding consultation fees, drugs, haemodialysis catheter insertion and travelling expenses. Peritoneal dialysis supply costs R12 000.00 per month, excluding the operation fees for insertion of a Tenckhoff Catheter, consultation and drugs. Kidney transplants cost \pm R116 000.00 and the cost of the transplant medication varies, depending on each patient's kidney functioning requirements. For example, normal transplant medication for a well-functioning transplanted kidney may cost between R3 000.00 – R5 000.00 per month, depending on the type of medication the patient is on.

1.3 PROBLEM STATEMENT

In the province of KwaZulu-Natal in South African, there are only three provincial hospitals that offer haemodialysis to patients with chronic renal failure that are awaiting renal transplantation. These hospitals are Addington, Grey's and King Edward VIII. Inkosi Albert Luthuli Central Hospital is the only hospital in KwaZulu-Natal that admits patients with both acute and chronic renal failure on haemodialysis as well as peritoneal dialysis.

The success of kidney transplants depends on a constant supply of suitable donors. Because of insufficient organ donors, however, the number of patients with chronic renal failure requiring kidney donation is rapidly increasing. With the low transplant rate in South Africa, haemodialysis units are saturated and it is becoming difficult to accommodate new patients unless they have a related donor or are able to undertake

continuous ambulatory peritoneal dialysis. However, having worked in a renal department for a period of twelve years, the researcher has realised that most of the near relatives of the patients who suffer from chronic renal failure are not keen to donate kidneys to their relatives or loved ones. This situation can only be curbed if members of the community come forward for live-related transplants, so that their loved ones with chronic renal failure can live a better life.

This study was seeking to address the following central question:

What are the perceptions of the relatives of patients suffering from chronic renal failure regarding kidney donation?

1.4 RESEARCH PURPOSE

The main purpose of the study was to explore and describe the perceptions of the relatives of patients suffering from chronic renal failure regarding kidney donation at a selected hospital in KwaZulu-Natal. Based on identified perceptions, recommendations will be made to promote relatives involvement in donating kidneys to their next of kin.

1.5 RESEARCH OBJECTIVES

The objectives of this research were to

- explore and describe the perceptions of relatives of patients suffering from chronic renal failure about donating kidneys
- explore and describe the reasons for and against kidney donations
- make recommendations to family members regarding kidney donation

1.6 THEORETICAL FRAMEWORK

The concept theoretical framework is described as an “explanation which is based on propositional statements resulting from an existing theory which seeks to create a specific way at looking at particular phenomenon” (Wood & Ross-Kerr 2006:51). The

researcher employed Potter and Perry's (2005) Health Belief Model to investigate how the relatives of patients suffering from chronic renal failure perceived kidney donation.

Potter and Perry (2005:91) define the health belief model as the relationship between a person's belief and behaviour. This relationship provides the way of clearly understanding how the participants behave in relation to their health and how they comply with health care therapies. The researcher decided to use this model to assist in understanding the factors influencing the relatives' perceptions about kidney donations.

This model has three components which are the individual's perceptions, modifying factors and likelihood of action. First of all, the participants were aware that their relatives are suffering from chronic illness and that one of the modalities of renal therapy is renal transplantation. Secondly, the researcher had to identify the perceptions of the impact of the current treatment of chronic renal failure, which is, in their case, haemodialysis. This also resulted to the identification of the impact of illness to the patients themselves and their socio-economic status. This perception may be influenced by the perceived threats of chronic renal failure as the debilitating disease. Thirdly, the likelihood that the participants take action regarding kidney donation to their relatives, will depend to their perceptions thereof. This then determined their attitude towards kidney donation.

1.6.1 Assumptions underlying the study

Assumptions are "basic principles that are believed to be true without proof or verification" (Polit & Beck 2008:14). In addition, Mouton (2004:123) states that assumptions "function as background beliefs that underlie other decisions in the research process". This is consistent with the views of Fox and Bayat (2007:140) and Burns and Grove (2008:474), who state that assumptions are something that are regarded as correct without verifying the underlying factors. This statement is supported by Hofstee (2006:88). The following assumptions were made by the researcher:

- First of all, the participants were aware that their relatives are suffering from chronic illness and that one of the modalities of renal therapy is transplantation.
- This perception is influenced by the perceived threat of chronic renal failure as the debilitating disease.

- The likelihood that the participants take action regarding kidney donation to their relatives depended on their perceptions. This then determined their perceptions and attitudes towards kidney donation.
- The participants were also able to identify the need for kidney donation and modify their perceptions and beliefs so as to give the “gift of life” to their beloved ones by becoming a donor.

1.7 DEFINITION OF KEY CONCEPTS

The conceptual and operational definitions of the key concepts used in this study are as follows:

1.7.1 Perceptions

Berman, Snyder, Kozier and Erb (2012:425) define perceptions as the way people interpret their beliefs, environment and practices. This definition is also further explained by Potter and Perry (2005:95) as an internal variable that influences an individual's beliefs and practices.

In this study, the term “perceptions” is used to describe the beliefs of relatives of patients suffering from chronic renal failure regarding kidney donation.

1.7.2 Chronic renal failure

Chronic renal failure is a progressive, irreversible renal function in which the body fails to maintain metabolic, fluid and electrolyte balance, resulting in uraemia or azotemia (Smeltzer, Bare, Hinkle & Cheever 2008:1527). Chronic renal failure, also known as chronic kidney disease, is a progressive loss of kidney function.

1.7.3 Kidney donation

According to Waugh and Grant (2006:336), a kidney is a bean-shaped organ, about 11 cm long, 6 cm wide, 3 cm thick and weighs 150 g. The Dictionary and Thesaurus (2006:506) defines a kidney as an organ that removes waste products from the blood and produces urine. According to Weller (2005:222), a kidney is one of two organs

situated in the lumbar region, which purify the blood and secrete urine. Erdei, Duret and Mironov (2010:135) define donation as “the contract whereby one party, called the donor, intentionally reduces its heritage with the liberal law for the other party, called the grantee, without watch for benefits”. A donation is a gift or a present (Dictionary and Thesaurus 2006:271).

In this study, the researcher uses the word “kidney” in relation to “donation”. Therefore, the term “kidney donation” applies to a living person giving one of their kidneys to a person who requires a kidney transplant.

1.7.4 Patient

A patient is a person who is ill or is undergoing treatment for a health care problem and/or is registered with a general practitioner (Weller 2005:295). Berman et al (2012:13) also define a patient as a person who is waiting for or undergoing medical treatment and care.

In the context of this study, the term “patient” focuses on patients suffering from chronic renal failure, who receive haemodialysis or are on peritoneal dialysis while waiting for kidney transplant.

1.7.5 Relatives

A relative is a member of the family or kin (Dictionary and Thesaurus 2006:768). In this study, the term “relative” refers to a near relative of someone who is suffering from renal failure and who is physically fit enough to donate a kidney to their beloved one, for example a. parent, daughter, son, uncle or cousin.

1.7.6 Suffering

Suffering means affected or troubled (Dictionary and Thesaurus 2006:768). In this study the researcher uses the word “suffering” in relation to patients who have been diagnosed with chronic renal failure. In other words, they are suffering from chronic renal failure.

1.8 RESEARCH DESIGN AND METHOD

The selection of a research methodology, according to Parahoo (2006:183), is the core of a research design and must include the research design, definition and selection of the population of interest, variables (characteristics of the individuals of this population), their status and the relationships to one another, the instrument for data collection and the procedure for data collection. A brief overview of the research design and methods utilised in this study is summarised. Chapter 3 contains a more extensive discussion on the research methodology.

1.8.1 Research design

This study will adopt a descriptive, exploratory qualitative design. Qualitative research is especially appropriate to the study of those perceptions best understood within their natural settings of experiments and surveys (Babbie & Mouton 2004:270). The researcher in qualitative paradigm does not attempt to control the context of the research, but rather attempts to capture that context in its entirety. Again, the research involves sustained interaction with the people being studied in their own language, and on their own turf (Brink 2007:11).

1.8.2 Research setting

The study was conducted in the haemodialysis unit of a selected hospital in KwaZulu-Natal, Durban as it is one of the few public hospitals in KwaZulu-Natal that provides haemodialysis to both acute and chronic renal patients. The researcher collected data from 45 relatives who accompanied patients suffering from chronic renal failure to the haemodialysis unit of the hospital.

1.8.2.1 Population

Parahoo (2006:256) defines the target population as a group from which a researcher aims to draw a sample. The target population, once defined, becomes the population of interest from whom the data can be collected. In fact, the target population is a subset of the theoretical population. The target population is the aggregate of cases about which the researcher would like to generalise (Polit & Beck 2008:338).

The accessible or source population is the aggregate of cases that conform to designated criteria and that are accessible as subjects for a study (Polit & Beck 2008:338).

1.8.2.2 *Criteria for inclusion*

The accessible populations for this study are patients with chronic renal failure and the near relatives who accompany their relatives to the haemodialysis unit at a selected hospital. The participants were accessed at the haemodialysis unit.

Eligibility criteria are the criteria that specify population characteristics (Polit & Beck 2008:338). The eligibility criteria for the participants is that they are the near relatives (parents, sisters, brothers, cousins, nephews, aunts, uncles) of patients with chronic renal failure and already on the kidney transplant waiting list. They were bringing or collecting their relatives from the haemodialysis unit in the selected hospital. These subjects were healthy and between 18 and 65 years old. The eligibility criteria for the participants was that a family member must be diagnosed with end-stage renal disease, be on haemodialysis and be eligible for a kidney transplant.

1.8.3 Sampling approach and technique

The researcher adopted a non-probability sampling approach and specifically applied the purposive sampling technique. With non-probability sampling, the chances of selection of the population units are not known in advance. Those who are available in the research field before the researcher arrives have a zero chance of selection, whereas the chances (of being selected) of those who would be interviewed are not known, as the potential number of all those who would be interviewed is also not known.

The approach in this study contributes to an understanding of phenomena. The researchers sample was chosen because it chooses the sample which can best provide the required data.

The researcher purposely selected the participants who comply with the eligibility criteria. Purposive sampling required the researcher to judge and select those subjects

who know the most about the phenomenon, and who are able to articulate and explain nuances to the researcher. In choosing a purposive sample, the researcher was guided by the research question and not tempted to choose samples out of convenience or leave it to others to make a selection (Parahoo 2006:208). Purposive sampling requires that the researcher exercises judgement by selecting the sample on the basis of knowledge of the population, its elements, and the research purpose (Babbie & Mouton 2004:166).

It is acknowledged that the major disadvantages of non-probability sampling are that it does not contribute to generalisation, that the extent of the sampling error cannot be estimated and that bias may be present (Brink 2007:132). This type of sampling may or may not accurately represent their population. It is usually more convenient and economical and allows the study of a population when they are not amenable to probability sampling, or when it is not possible to locate the entire population (Brink 2007:131). Researchers may not be concerned with the typical experience of the population and therefore not interested in generalisability. Instead they may be more concerned with understanding the experience of social segments of the population, or interested in studying rare or unpredictable phenomena (Brink 2007:132).

In this study, the researcher collected data only from those relatives that were available during the data collection period and had focus on their perceptions of organ donation. The information from the sample selected would differ from the rest of the population

1.8.4 Sample

In qualitative research, the researcher gathers the data until the point of saturation has been achieved. The sample size is therefore not pre-determined. The proposition that a larger sample is better does not apply in qualitative studies, where the type of sample is usually purposive. Too many subjects would cloud the issues and increase the complexity of the analysis process (Brink 2007:136).

1.8.5 Data collection approach and method

The researcher applied an unstructured self-report method, namely individual interviews, in conjunction with participant observation. Polit and Beck (2008:324) define

unstructured self-report technique as “the study where the participants respond to a series of questions posed by the researcher”. According to Babbie and Mouton (2004:289), an unstructured interview is “an open interview which allows the object of study to speak for him/herself. The unstructured interviews are the mode of choice when researchers do not have a clear idea of what it is that they do not know” (Polit & Beck 2008:392). The purpose of questions was to find out their thoughts, perceptions, attitudes, beliefs, feelings, motives, plans, experiences, knowledge levels and memories (Brink 2007:136).

Parahoo (2006:321) defines unstructured interview as a “synonym of qualitative interview, which is an 'in-depth', 'informal', 'non-directive', 'focused' and 'open'”. According to Brink (2007:152), unstructured interviews are more free-flowing, with their structure being limited only by the focus of the research.

Unstructured interviews are conducted more like a normal conversation, but with a purpose (Brink 2007:152). Unstructured interviews leave the wording and the organisation of questions, and sometimes even the topic, to the discretion of the interviewer (Brink 2007:152). Unstructured interviews are conducted more like a normal conversation, but with a purpose (Brink 2007:152). Unstructured interviews leave the wording and the organisation of questions, and sometimes even the topic, to the discretion of the interviewer (Brink 2007:152). The researcher was using an interview schedule which helped to limit the researcher's influence on the interview, but allowed for flexibility and probing.

As the researcher was using unstructured interviews, she was able to gather rich data from the subjects as she asked about their perceptions regarding kidney donation. The researcher was able to elicit data about any perceptions that influence the participants in deciding whether to donate their kidneys or not.

1.8.6 Data collection

The researcher asked prompting questions that encouraged the respondents to elaborate on the central question that was being discussed. It is necessary that researchers set aside their preconceived ideas and expectations to prevent themselves from influencing the participants. Wording questions is a tricky business and that is the

reason why the researcher in this study will use probing to get answers in more depth without biasing later answers (Babbie & Mouton 2004:289).

Bhengu and Uys (2004:24) cited that the lack of knowledge about organ donation and transplantation among the Zulu-speaking people is related to their traditional Zulu life patterns, beliefs about death, burial and life thereafter and their values, as well as their social structures. Bhengu and Uys (2004:24) further argued that culture sensitivity and culture congruency must be borne in mind during the promotion of organ donation among Zulu-speaking people. The participants in this study were from different cultural backgrounds, therefore it was necessary for the researcher to be culturally competent and apply her knowledge of the different cultures.

1.8.7 Data analysis

Data analysis is generally not a distinct step in qualitative research studies, but is done concurrently with data collection, unlike quantitative research analysis, which does not begin until all data has been collected. The different forms of qualitative approaches have different forms of analysis (Brink 2007:184). In this study, data was transcribed by the researcher.

In general, qualitative data analysis involves three levels of analysis: basic, intermediate and higher. The process of data analysis commenced as the researcher started to break data into as many parts or categories as she could identify. This was followed by grouping together some of these parts into manageable themes based on their similarities. The final part of the process was to put the themes together in order to describe the 'whole'. Thus, the researcher was incorporating the basic, intermediate and higher levels of analysis, which will facilitate the process. These levels are neither distinct nor linear. The researcher continually moved backward and forward between these levels or stages, until a comprehensive understanding of the phenomenon as a 'whole' is ready to be reported (Parahoo 2006:393).

Switching from one language to the other helped the researcher and the participants to establish better communication and a closer relationship. Semi-structured interviews were centered on the participants' language of choice, accommodation strategies and

code switching. The questions asked helped the researcher to identify the accommodation strategies.

Creswell (2007:237) cited that data analysis needs to be done sequentially so that data is well organised and easily interpreted. During data collection, data is so segmented and the researcher needed to ensure that it becomes organised as a whole. To ensure this, the researcher had to read through the data and start analysing with a coding process. The researcher then described participants, setting, categories and themes. The next step was to determine how these categories were to be presented. This led the researcher to the stage of interpreting the meaning of the data.

1.9 ETHICAL CONSIDERATIONS

The researcher ensured that the need to obtain data does not take precedence over subjects' needs, wishes and rights. There are a number of procedures and mechanisms that were used in the course of the study to ensure that human rights are protected. These include procedures for obtaining informed consent (Annexure E), maintaining privacy and for risk/benefit assessment.

1.9.1 Protecting the rights of the participants

The researcher had the responsibility of ensuring that the rights of the participants are always protected. This means that the researcher had to conduct research in an ethical manner so as to prevent it having negative consequences (Brink 2007:30).

1.9.1.1 *Autonomy and informed consent*

Participants should be treated as autonomous agents, capable of controlling their own activities. The participants have the right to decide voluntarily whether to participate in a study, without risking any penalty or prejudicial treatment. It also means that “people have the right to ask questions, to refuse to give information or to withdraw from the study” (Brink 2007:39; Polit & Beck 2008:172).

Research participants who are fully informed about the nature of the research, the demands it will make on them, and the potential costs and benefits to be incurred are in

a position to make thoughtful decisions regarding participation in the study (Polit & Beck 2008:176-177). “Qualitative researchers do not always know in advance how the study will evolve. Because the research design emerges during the data collection and analysis process, the researcher may not know the exact nature of the data to be collected, what the risks and benefits to participants will be, nor how of time commitment they will be expected to make. Thus in a qualitative study, consent is often viewed as an ongoing, translated process, referred to as process consent study” (Polit & Beck 2008:177).

The informed consent (Annexure E) must be obtained prior to commencement of a study. According to Brink (2007:35), “the informed consent form has three major elements, which are:

1. The type of information needed for the research subject.
2. The degree of understanding that the subject must have in order to give consent.
3. The fact that the subject has the choice of whether or not to give the consent”.

In this study, informed consent was obtained from the participants after thoroughly explaining the research purpose and the significance of the study. The researcher had to ensure that the participants understood the information prior to asking them to sign the consent form. The researcher also ensured that the consent is given voluntarily.

1.9.1.2 Justice

The principle of justice includes the subjects’ rights to fair selection and treatment, and their right to privacy. Participants should be selected for reasons directly related to the problem being studied, and not because they are easily available, easily manipulated, or poor, or because the researcher likes them and wants them to receive the specific benefit of a study (Brink 2007:33). The researcher respected the participants’ rights to privacy by ensuring that interviews are conducted in a separate room. The participants had the right to determine the extent to which, and the general circumstances under which, their private information would be shared with or withheld from others (Brink 2007:33). The researcher had to ensure that a thorough explanation is given to the participants on how their participation will contribute to the study.

1.9.1.3 Anonymity

Anonymity literally means namelessness. The process of ensuring anonymity refers to the researcher's act of keeping the participants' identities a secret with regard to their participation in the research study. In fact, it is preferable that even the researcher should not be able to link a participant with his/her data (Brink 2007:34). To ensure anonymity in this study, the researcher used numbers or code names for the respondents and the master list of the participants will be kept in a separate location. The list of the actual names will be destroyed so that the participants remain completely anonymous.

1.9.1.4 Confidentiality

Confidentiality refers to the researcher's responsibility to prevent all data gathered during the study from being divulged or made available to any other person (Brink 2007:35). This means that the researched data should never be shared with any outsiders. It should be kept closed and only people involved in the research should have access to it, unless the researcher has been given explicit permission to make it known. Before the research subjects consent to participate, they must be told that the researcher intends to publish the results of the study, but that she will make every effort to group the obtained data so that personal characteristics will not be made known.

1.9.1.5 Respect

This is the principle of self-determination, which means that humans should be treated as autonomous agents, capable of controlling their own activities. The participants have the right to decide voluntarily whether to participate in the study, without risking any penalty or prejudicial treatment. They were informed that their participation or non-participation will not compromise the treatment received by their sick relative.

Culture care theory reflects a deep respect for people from diverse cultures and the need for care decisions that respect the clients' choices, which are guided by and consistent with their natural care values, expressions and meanings. The researcher respected the participants' views on health, illness and organ donation, even if their views are unscientific (Leininger & McFarland 2002:173). It is also important for the

researcher to be sensitive to and have respect for the beliefs, habits, and lifestyles of people from different cultures. The researcher had to be courteous and apply tact at all times.

1.9.1.6 *Beneficence and non-maleficence*

Beneficence involves an effort to ensure that the research project benefits not only the participating individuals, but also society in general by contributing to the pool of human knowledge (Parahoo 2006:111). Non-maleficence involves that the researcher should do no harm to participants (Parahoo 2006:112).

While potential physical harm may be obvious, psychological effects may not be as transparent (Polit & Beck 2008:112). It is, therefore, very important that the researcher considers the risk-benefit ratio before beginning the study. The general guideline is that the risk should not exceed the potential benefits to be gained by the study. When the risk is high, the researcher had to make every effort to reduce it and to maximise the benefits.

There are emotional risks involved in this study whereby some participants would feel that their delay in considering kidney donation could have been detrimental to the condition of their beloved ones (Brink 2007:34). Other risks are that family members would feel pressurised to donate a kidney, feel guilty because they do not want to donate a kidney or family members and patients may have a renewed sense of threat of death. If the perceived risks and costs to subjects outweigh the anticipated benefits of the research, it would not be undertaken. In this study, the researcher explained the specific risks and benefits of participation before its inception.

Both the participants and the researcher benefited from the study. The participants gained more information regarding kidney donation. In order for the researcher to be able to ensure that the risk is not exceeding the potential benefit, the researcher used her transcultural knowledge requiring realistic and sensitive understanding of people. What was most crucial, however, is that the researcher listens to the participants with a very open mind, learning from them, but not imposing her own ideas on them.

The researcher avoided exploitation of the participants by giving them the opportunity to ask questions or make complaints. Willingness of the participants to participate in the study was always ensured so as to maintain cooperation and harmony throughout the study.

1.9.2 Protecting the rights of the institution

Most institutions have set up independent committees to review proposed research and to examine and monitor the ethical standards of ongoing research. Researchers submit their research proposals along with the necessary consent forms to the appropriate committee for review, prior to beginning the research project. The members may refuse permission for the researcher to carry out the study, or they may recommend certain changes to the research proposal if they are not satisfied that it is in accordance with the established scientific and ethical guidelines (Brink 2007:42).

The research proposal was submitted to the Research Ethics Committee (Annexure C) or review board in the hospital where research will take place, to be scrutinised before it is put into operation. The Research and Ethics Committee, Department of Health Studies, University of South Africa also gave the ethical clearance (Annexure A). They would have refused permission to carry out research, or they would have recommended changes to the research proposal if they were not satisfied that it is in accordance with the established scientific and ethical guidelines.

1.9.3 Scientific integrity of the research

The researcher has ethical responsibilities associated with the conduct and reporting of the research. The researcher must demonstrate competency, accuracy and, above all, honesty in whatever she does. It is also important that the researcher has the ability to manage resources, whether financial, human or material, effectively, efficiently and economically (Brink 2007:40-41).

In order to be honest, the researcher avoided fabrication, manipulation of designs and methods, selective retainment and/or manipulation of data, plagiarism and irresponsible collaboration.

1.10 SIGNIFICANCE OF THE STUDY

The study revealed the perceptions and beliefs of living relatives influencing decisions on kidney donation to their relatives suffering from chronic renal failure. The perceptions and beliefs of the relatives will enable the researcher and the members of the multidisciplinary health team to identify the barriers to organ donation and to address them accordingly. The relatives of patients with chronic renal failure will be able to avail themselves for kidney donation.

1.11 SCOPE AND LIMITATIONS OF THE STUDY

The study population was not be fully represented because there are many chronic renal failure patients who are awaiting renal transplantation and are on peritoneal dialysis in their homes or residential areas. This group of the population was not presented in the study. To overcome this, the researcher ensured that the participants include relatives of people who were on peritoneal dialysis before starting haemodialysis.

Haemodialysis is a prescribed treatment by nephrologists and patients' requirements for haemodialysis differ. Some patients dialyse once a week, others twice a week and the majority three times a week. As the researcher will be conducting her study on Mondays, Wednesdays and Fridays, which are the busiest days in the haemodialysis unit, those (probably new) patients who go for haemodialysis once a week, which is usually on Tuesdays, were omitted from the study.

1.12 STRUCTURE OF THE DISSERTATION

Chapter 1: Orientation to the study

Chapter 2: Literature review

Chapter 3: Research design and methodology

Chapter 4: Analysis, presentation and description of research findings

1.13 CONCLUSION

The researcher has described the research problem, as well as its background. The aims of the research study and its significance have led the researcher to using a qualitative exploratory and descriptive research design, more specifically, the Health Belief Model. Individual unstructured interviews enabled the researcher to gather in-depth information on the participants' perceptions, religious beliefs and attitudes. Ethical consideration for the participants, the institution as well as the trustworthiness of the study was well implemented by the researcher.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter presents the literature review, which is centred on kidney donations and the perceptions of relatives of patients with chronic renal failure. This study focuses on the different perspectives of kidney donation of the relatives of patients suffering from chronic renal failure. It is important to have an understanding of this complexity to ensure that the quality of life of the both the donor and the recipient is not harmed (Crombie & Franklin 2006:196-210). This chapter will contribute to the understanding of chronic renal failure as well as its modalities of treatment. The concept of illness perceptions is useful in understanding the impact of end-stage renal disease and dialysis treatment on quality of life (Skorecki, Green & Brenner 2005:1653). Facilitated advanced care planning through the provision of timely appropriate information can positively enhance rather than diminish patients' hope.

2.2 CHRONIC RENAL FAILURE

When a patient is diagnosed with chronic renal failure, it means that the kidney functioning has progressively declined over period of time, which can be weeks, months or even a slow progression over years. Chronic renal failure is the stage when the patient depends on some form of dialysis or a kidney transplant in order to survive (White et al 2008:229-237).

2.2.1 Definition of chronic renal failure

According to Smeltzer et al (2008:1527), chronic renal failure or end-stage renal disease is progressive and irreversible, and there is a markable deterioration in renal functioning in which the body's ability to maintain metabolic, fluid and electrolyte balance fails, resulting in uraemia and azotemia. Skorecki et al (2005:1653) define chronic renal failure as a pathophysiological process with multiple aetiologies, resulting

in the inexorable attrition of a number of nephrons as well as their functioning. In turn, end-stage renal disease represents a clinical state or condition in which there has been an irreversible loss of endogenous renal function, of a degree sufficient to render the patient permanently dependent upon renal replacement therapy in order to avoid life-threatening uraemia.

Life threatening uraemia can be identified by anorexia, lethargy, confusion and coma. Other signs and symptoms include nausea, vomiting, shortness of breath and seizures (Meyer, Hostetter & Uremia 2007:1316-1325).

2.2.2 Impact of chronic renal failure on family members and public health

Nicholas (2005:45-52) argues that the family of patients with chronic renal failure become stressed due to the implications brought about by end-stage renal disease. This becomes an extra burden to the family members because it can lead to poor performance at work due to frequent hospital visits for dialysis, appointments and hospitalisation. In many cases, the patients' lives could be prolonged by dialysis and a kidney transplant, yet they are excluded from the transplant programme because they are unable to afford the medical bills and transport costs to the haemodialysis centre, sometimes two or three times a week.

According to Williams and Manias (2008:69-81), chronic kidney disease is a concern for public health worldwide because of the expense of the treatment that is rendered. This situation is exacerbated in developing countries where the majority of patients are from a low socio-economic background and are treated in public hospitals because they cannot afford private medical assistance. Early diagnosis of chronic kidney disease, more aggressive management of co-morbid conditions and complications, and early nephrologists' referral are three key elements required to elevate the standards of care for chronic kidney disease and end-stage renal disease. Amedia and Perazella (2006:311-315) argue that through recognising the direct and indirect disease burdens, tracking outcomes of interventions, and sharing this information in a timely manner, care management professionals can overcome the provider/payer data gap and achieve better outcomes.

2.2.3 Brief causes of chronic renal failure

According to Skorecki et al (2005:1653), causes of chronic renal failure include recurring pyelonephritis; polycystic kidney disease; autoimmune disorders, such as systemic lupus erythematosus; hardening of the blood vessels damaging the blood vessels of the kidneys; urinary tract blockage and reflux due to frequent stones; as well as excessive use of medications that are metabolised through the kidneys.

According to Warady and Chadha (2007:1999), detailed information on the etiology of chronic renal failure is unavailable from many underdeveloped countries owing to poor data collection and the absence of renal registries. In addition, and in contrast to the experience within developed countries, many of these countries continue to suffer from the burden of infectious diseases such as hepatitis C, malaria, schistosomiasis, and tuberculosis, with resultant infection-related glomerulonephritis. These authors argue that one such example is Nigeria, from which a publication on pediatric chronic renal failure reported various glomerulopathies as the cause of renal failure in one half of their patients, a third of whom also had nephrotic syndrome. Poor or insufficient statistics are also noted in relation Human Immunodeficiency Virus (HIV) associated nephropathy in children, a disorder that is likely to increase along with the increasing incidence of HIV in Africa and Asia. Warady and Chadha (2007:1999) also cited that Familial Mediterranean Fever leading to amyloidosis has been found to be responsible for up to 10% of cases of chronic renal failure in Turkish children ($n = 459$).

2.2.4 Global prevalence and incidence of chronic renal failure

According to Atkins (2005:67), approximately 30% of patients with diabetic nephropathy progress to chronic renal failure, with some dying of cardiovascular disease before they reach the end-stage of renal failure. Clinical signs identified are including micro albuminuria and subsequently proteinuria. It is therefore very important to assess patients thoroughly so as to detect abnormalities at an earlier stage before complications occur. These preventive measures are not only for diabetic or hypertensive patients, but for all patients who are being screened at a primary health care level.

Atkins (2005:67) further states that the incidence of patients with end-stage renal disease being treated by renal replacement therapy varies enormously depending on the level of affluence of the country. The highly developed countries such as North America, Europe and Japan have the highest incident rates of treated end-stage renal failure, whereas the emerging countries have very low incident rates. There are now over 1 million dialysis patients worldwide, with an incidence of about a quarter of a million new patients each year. The annual incidence of new cases of end-stage renal failure in Hong Kong reflected in their renal registry data demonstrates the worldwide trend of progressively increasing numbers. In 1996, there were 100 patients per million population beginning dialysis in Hong Kong. In the year 2000, this increased to 122 patients, while in 2003, 140 patients per million population began treatment for end-stage renal failure. Similarly, the rates have been increasing in the United States, and it is predicted that by 2010, there will be almost 700,000 dialysis patients in the United States, costing about US\$30 million a year for their dialysis treatment. Obviously, treatment of such an ever-increasing burden of end-stage kidney failure cannot be afforded, even in the wealthiest of countries (Atkins 2005:68).

Although parents of children diagnosed with chronic kidney disease become psychosocially, physically and financially stressed, their children depend on them for complex, continuous and intensive support. This can affect their ability to cope and influence the quality of care they provide for their child. Another problem that the parents encounter is that the healthcare offered by professionals is often centred on the technical and medical interventions, while strategies explicitly targeting parental support are often not considered (Atkins 2005:68).

Redmond and McClelland (2006:48) also argue that chronic renal failure is a major public health issue, but that early treatment interventions for chronic kidney disease will delay, if not prevent, progression to established renal failure. According to Gerson, Butler, Moxey-Mims, Wentz, Shinnar, Lande, Mendley, Warady, Furth and Hooper (2006:208-215), renal failure in early childhood is very progressive and becomes a non-curable condition. Fortunately, improved identification of kidney problems allows for early intervention, which is thought to slow progression towards end-stage renal disease. Gerson et al (2006:208-215), further state that medical interventions for pediatric end-stage renal disease have also improved and this allows children to be on renal replacement therapies as well as transplantation lists.

2.2.5 Stages of chronic renal failure

Redmond and McClelland (2006:49) emphasised the importance of early identification of the various stages of chronic renal failure so as to allow for early intervention to reduce cardiovascular risk, progression and the need for dialysis. Serum creatinine measurement is a traditional marker of renal function and is calculated at the rate of production of creatinine, which is dependent on muscle mass and the rate at which the kidney excretes creatinine. According to these authors, glomerular filtration rate is the best measure of overall kidney function and progression of renal failure, explaining that the glomerular filtration rate is the volume of water filtered out of the plasma through the glomerular capillary walls into the Bowman's capsules per unit of time.

Skorecki et al (2005:1653) identify the stages of chronic renal failure in relation to glomerular filtration rate as follows:

Table 2.1 Stages of chronic renal failure in relation to glomerular filtration rate

Stage	Glomerular Filtration Rate (GFR)	Description
1	90 and above	Kidney damage with normal or increased glomerular filtration rate
2	60-89	Kidney damage with mildly increased glomerular filtration rate
3	30-59	Moderately decreased glomerular filtration rate
4	15-29	Severely decreased glomerular filtration rate
5	14 or less	Renal failure

Stage 2 kidney disease is a tricky area, because normal glomerular filtration rate falls with age, and therefore many normal older people may fall into this category. Equations used to predict glomerular filtration rate (rather than real measurements) may also give falsely low results in people with near-normal function.

Patients don't usually feel unwell during the first three stages of kidney disease, as this usually begins at stage 4. Despite this, during the first three stages, patients are at risk of their kidney disease increasing in severity and are also at increased risk of heart disease or other illnesses affecting arteries. Gerson et al (2006:208-215) state "given

the rise in chronic kidney disease in both children and adults, chronic kidney disease has been targeted as a public priority.”

2.2.6 Treatment options for chronic renal failure

There are various factors that play a significant role in making a decision whether to use haemodialysis or peritoneal dialysis on patients with chronic renal failure. The factors involved include their age, the presence of co-morbid conditions, the ability to perform the procedure, and the patient’s own conceptions about the therapy (Singh & Brenner 2005:1663).

According to Niu and Li (2005:15-21), patients with chronic renal failure need renal replacement therapy as a substitute for their original kidneys. Different renal replacement therapies have different levels of impact on physical, psychological and social health. Quality of life as perceived by patients with chronic renal failure is an important measure of patient outcome. It is the quality of life of patients having various types of renal replacement therapy that will assist physicians, nurses, patients and their families to make decisions on treatment selection. Niu and Li (2005:15-21) further argue that there is a need to establish support groups for patients having renal replacement therapy in order to enhance their quality of life, especially in the psychological domain.

2.3 HAEMODIALYSIS

2.3.1 Definition of haemodialysis

Singh and Brenner (2005:1664) define haemodialysis as the movement of metabolic waste products from the circulation, through vascular access into the dialysate on the haemodialysis machine.

2.3.2 Description of haemodialysis

According to Smeltzer et al (2008:1537), haemodialysis is a process during which the blood, laden with toxins and nitrogenous waste, is diverted from the patient to a machine, a dialyser, which removes the toxins, before returning the blood to the patient. The procedure involves pumping heparinised blood through the dialyser at a flow rate of

300 to 500 ml/min while dialysate flows in an opposite counter-current direction at 500-800 ml/min.

2.3.3 Objectives of haemodialysis

The main objective of haemodialysis is to extract toxic nitrogenous substances from the blood as well as ultrafiltration. The procedure is targeted at removing both low and high molecular weight solutes.

This option of treatment is used for patients who are acutely ill and require short-term dialysis and for patients with chronic renal failure who require long term or permanent therapy (Singh & Brenner 2005:1665).

2.3.4 Types of accesses used for haemodialysis

According to Amedia and Perazella (2006:311-315), the transition from chronic kidney disease to end-stage renal disease becomes critical and vascular access becomes necessary to support haemodialysis in an outpatient or inpatient setting.

- A native fistula is created by the anastomosis of an artery to a vein and this result into arterialisation of the vein. The patient is sent to theatre for this vascular operation and to have the fistula created. The fistula is not used for a minimal period of six weeks until it is well matured and has a good bruit.
- A double lumen catheter (commonly called the subclavian catheter) is the option of choice when emergency access for haemodialysis is needed. This catheter is inserted in either the femoral, internal jugular or subclavian veins.

2.3.5 Incidence of haemodialysis

With the low transplant rate in South Africa, haemodialysis units have become saturated and it is becoming difficult to accommodate new patients unless they have a related donor or are able to undertake continuous ambulatory peritoneal dialysis.

Kontodimopoulos and Niakas (2008:85-96), in their study, “An estimate of lifelong costs and quality adjusted life years in renal-replacement therapy based on patients’ life expectancy”, which was conducted at Hellenic Open University in Greece, concluded that because haemodialysis is used by 75% of the Greek end-stage renal disease patients, cost saving efforts must be intensified. They recommended reconsidering supply and reimbursement policies for dialysis and drugs, establishing satellite dialysis units and adopting telemedicine in remote areas could be explored, as well as efforts for disseminating the idea of organ donation.

2.3.6 Effects on the patient

End-stage renal disease is a chronic progressive disease with renal transplantation as a major treatment option. However, the majority of patients choose haemodialysis as their primary treatment. In this disease, many changes occur in the body that demand adjustments in almost every aspect of these patients' lives (Tanyi & Werner 2008:43-50).

Gordon (2001:971-987) cited that the relationship between treatment decisions and ethnicity is inconclusive due to multiple, interrelated covariates. The most common reasons patients reported for remaining on dialysis included doing well on haemodialysis, fear of surgery for the insertion and removal of a Tenckhoff catheter, and knowing other patients whose kidney transplants had failed.

According to Silva, Signori, Signori, Moreno, Barros, Bella-Klein, Schaan and Irigoyen (2008:482-488), haemodialysis improves endothelial venous function, in association with an antioxidant effect. This was their finding in the study to determine the acute effect of haemodialysis on endothelial venous function and oxidative stress.

O'Sullivan and McCarthy (2007:276-284), in their study of exploration of the relationship between fatigue and physical functioning in patients with chronic renal failure receiving haemodialysis, indicate the prevalence of fatigue and limitations in physical functioning in individuals. This is proved by the fact that when patients come from haemodialysis session, they are always weak and tired and those traveling long distances for haemodialysis suffer the worst from fatigue.

According to Hanly (2007:59-66), haemodialysis also causes sleep disruption and sleep loss, and may further increase the considerable cardiovascular morbidity and mortality in this patient population. Renal transplantation is therefore more effective in prevention of complications.

2.4 PERITONEAL DIALYSIS

2.4.1 Definition of peritoneal dialysis

Kasper et al (2005:1667) define peritoneal dialysis as when the toxic materials are removed through a combination of a convective clearance generated through ultrafiltration, and diffusive clearance down a concentration gradient via the peritoneal dialysis catheter. The Tenckhoff catheter acts as a mode of access for a dialysis solution to the peritoneal cavity. Dialysis takes place four times a day, seven days a week, but can be performed almost anywhere. Again, this treatment is for life, or until a transplant donor is found.

2.4.2 Description of peritoneal dialysis

Absorption of solutes and water from the peritoneal cavity occurs across the peritoneal membrane into the peritoneal capillary circulation. The waste products normally excreted by the kidneys, are cleared from the blood by diffusion and osmosis as the waste products move from higher concentration to lower concentration across the semi-permeable membrane. Dialysate is infused into the peritoneal cavity by gravity, after which the clamp on the infusion line is closed. After a dwell time (when the dialysate is in the peritoneal cavity), the drainage tube is unclamped and the fluid drains from the peritoneal cavity, again by gravity. A new container of dialysate is infused as soon as drainage is complete. The duration of the dwell time depends on the type of peritoneal dialysis (Smeltzer et al 2008:1545).

2.4.3 Objectives of peritoneal dialysis

The main goal for peritoneal dialysis is to reserve the residual functioning of the kidney while also removing the toxic waste circulating in the body through the peritoneal dialysate fluid.

2.4.4 Access used for peritoneal dialysis

Access is obtained to the peritoneal cavity through a peritoneal catheter. The acute peritoneal catheters (also called stick catheters) are inserted at the bedside, while the chronic peritoneal catheters (also called Tenckhoff catheters) are inserted in an operating theatre.

2.4.5 Incidence of peritoneal dialysis

Few units offer continuous ambulatory peritoneal dialysis and these are predominantly in South Africa, Kenya, Nigeria, Sudan, Senegal, Namibia and Botswana. In some of these countries, this modality is the only way to manage end-stage renal disease because no functional haemodialysis units are available. However, all components must be imported, which makes continuous ambulatory peritoneal dialysis even more expensive than haemodialysis as an option (Naicker 2003:7).

2.4.6 Effects on patients

Cost considerations, the high incidence of peritonitis and the absence of resources to manage it when it occurs, make peritoneal dialysis an unattractive option in the management of chronic renal failure in sub-Saharan Africa.

According to Cleary and Drennan (2005:577-586), end-stage renal disease and its ensuing treatments negatively affect quality of life. Peritonitis and the high cost of peritoneal dialysis fluids also limit this option. Bamgoye (2006:5-9) states that peritoneal dialysis, including the fluids, must be imported, which makes continuous ambulatory peritoneal dialysis even more expensive than haemodialysis as an option. Most chronic renal failure patients are on haemodialysis because it is the only modality of management available in most countries in the sub-region.

2.5 KIDNEY TRANSPLANTATION AS A VIABLE TREATMENT OPTION

2.5.1 Definitions of related concepts

2.5.1.1 *Kidney*

Berman et al (2010:1285) define kidneys as bean-shaped organs situated on either side of the spinal column, behind the peritoneal cavity. The right kidney is slightly lower than the left, due to the position of the liver. They further state that kidneys are the primary regulators of fluid and acid-base balance in the body.

2.5.1.2 *Donation*

According to the Compact Oxford Dictionary and Thesaurus, and Work Power Guide (2006:271) a donation means a gift, contribution, present or offering.

2.5.1.3 *Kidney donation*

Kidney donation literally means giving a “gift of life” since a donor will be giving another person a second chance of life. This involves the actual transplantation of a viable kidney from the donor to the recipient who will be suffering from chronic renal failure and is in desperate need of a kidney in order to survive. In this study, the word “kidney” is used in relation to “donation” as “kidney donation” focuses on a living person giving a kidney to a person who requires a kidney transplant.

2.5.2 The legal aspects of kidney donation

The donation of human tissue is governed by the Human Tissue Act 65 of 1983, as amended, but will be replaced by chapter 8 of the National Health Act 61 of 2003 when this chapter is brought into effect. The act states that “it is an offense to charge a fee in relation to the donation of human organs.” The law protects the donor’s rights and dignity in respect of their integrity, without discrimination. For transplantation laws to be ethically and legally acceptable, they need to be consistent with the international standards of the World Health Organization. This will therefore ensure that the

transplantation laws provide for a system to ensure equitable access to transplantation services to patients (Satyapal 2005:150-153).

In South Africa, if anyone wishes to donate their organ/s in cases of accidental death or certified brain dead, they have to register with the Organ Donor Foundation, which is a non-governmental organisation. An organ donor card is then sent to those individuals, who need to carry it in their wallets at all times. If involved in an accident and certified dead, the transplant coordinator will be contacted, and the next-of-kin will be informed of the patients' wishes so as to get the informed consent before the kidneys are harvested.

Because of financial constraints, the National Health Department of South Africa, in consultation with the nephrologists, has formalised a protocol for the management of end-stage renal failure. State facilities will only offer renal replacement therapy to patients who are eligible for a transplant (Naicker 2003:121).

There are no constraints for sex, race or social status and dialysis is offered to transplantable patients who are able to attend for treatment. Transplantation of organs from living unrelated donors requires permission from the Minister of Health (Naicker 2003:121).

2.5.3 Living donor transplantation

2.5.3.1 *The recipient*

Kidney transplantation requires that the recipient be first accepted on the Kidney Transplantation Programme. The patient is accepted on this programme only after a thorough assessment by the nephrologists to exclude medical conditions such as cardiac and psychiatric diseases, substance abuse and malignancies. This involves a physical examination and screening tests (e.g. HIV, hepatitis, cytomegalovirus and Ebstein-Barr virus, vital organs functioning and any other potential sources of infection) and performing diagnostic tests) (Yang 2007:1542-1551).

2.5.3.2 *The donor*

Living donors need to be between the ages of 18 and the early 70s and can include parents, children, siblings, other relatives and friends. The donor needs intensive screening to be done. This includes a series of laboratory and X-ray tests. Screening is done for kidneys (urinary testing and CT angiogram) and liver functioning, heart diseases, lung diseases as well as past exposure to viral illness. These tests are done in a hospital on an out-patient basis to ensure medical clearance for pre-existing conditions. It is very important that the donor and the recipient be histocompatible, thereby minimising genetic disparity. This is ensured by doing the blood grouping (ABO) and tissue typing (Human Leukocyte Antigen [HLA]) (Yang 2007:1542-1551).

Lennerling, Forsberg and Nyberg (2003:1243-1247) explain that the criteria for becoming a living donor has expanded as compared to early years where only parents and siblings were accepted, as it now includes cousins, uncles, aunts, spouses and close friends.

2.5.3.3 *The role of the Kidney Transplantation Multidisciplinary Committee*

An aspect of kidney transplantation from a living donor that is very important to understand is that it involves both the donor, who is giving the kidney, and the patient, who is receiving it, and that this takes place during an intensive operation called a kidney transplant. Kidney transplantation, therefore, is a procedure that is not undertaken lightly and acceptance onto the programme is determined by the Kidney Transplant Multidisciplinary Committee.

The Kidney Transplant Multidisciplinary Committee includes transplant surgeons, nephrologists, psychologists, nurses, social workers and the transplant coordinator. This committee meets on regular basis to discuss patients who are being considered for the chronic dialysis programme, as well as kidney transplantation.

The initial interaction for donors is with a dedicated transplant coordinator who remains the primary point of contact throughout the donor evaluation, surgery and post-operatively. This facilitates a collaborative approach, recognising the interplay of factors considered in the donor's autonomous decision to move forward or not (Site, Freeman,

Harper, Waters & Pruett 2008:287). The social worker schedules appointments with the recipient so as to assess social aspects to ensure that the patient conforms with the selection criteria. Prospective donors are excluded from the programme by certain social aspects, such as lack of running water, lack of transport, which would preclude them from going to hospital should an urgent need arise, no fixed abode, poor socio-economic status and a poor support structure. A psychologist will also schedule an appointment so as to assess the psychological well-being of the patient, including their motivation to donate without remuneration.

Once all the investigations for kidney transplant have been done, the donor and the recipient are presented in the Kidney Transplantation Multidisciplinary Committee for discussion. The team considers the benefits as well as the risks of kidney transplant. It is then decided whether the kidney transplant will proceed or not (Renal Resource Centre 2009:19).

The transplant surgeon, as a team member, checks his operation schedule to see when the transplantation can be done. Once the transplant date is confirmed, the donor and the recipient are called to the renal clinic for finalisation of the whole process of transplantation. This provides another opportunity for any questions and answers. The informed consent is then signed by the donor.

The findings of the multidisciplinary committee indicate the degree and nature of the dependence and interdependence felt between donors and recipients; the difficulties encountered between both; the decision to donate or refusal to donate; the longer term obligations that may arise; and the impact on the family unit, demonstrating psychological, social, and cultural risks within the live donation process. Cronin (2008:129-132) argues that the worldwide shortage of organs for transplantation means that “every year thousands of individuals who value their life die needlessly”. This is an unacceptable loss of human life. Saving a life is one of the most wonderful things one individual can do for another.

Site et al (2008:284) explained that education of the patients by the Multidisciplinary Ethics Committee is crucial to ensure that a well informed decision is taken by the relatives who want to donate their kidneys. These authors further argue that

communication skills as well as showing respect to the prospective donor can create an opportunity for them to make an autonomous informed decision.

2.5.4 Cadaver donor versus living donor

Kidney transplantation is also a viable treatment option if the kidneys are donated from a cadaver. When patients are accepted on the Kidney Transplant Programme, they will be placed on a waiting list for cadaver kidneys if an organ from a living donor (usually a relative) is not available. These patients must be ready to come to hospital for the transplant as soon as matching kidneys become available.

Morgan, Mayblin and Jones (2008:147-158) cited that studies of attitudes towards cadaver kidney donation have failed to adequately explain the disproportionately low rates of cadaver organ donation among ethnic minorities. This reflects lack of knowledge and general information regarding chronic renal failure and kidney donation. According to Merion, Ashby, Wolfe, Distant, Hulbert-Shearon, Metzger, Ojo and Port (2005:2726-2733), transplantation using kidneys from a deceased donor is associated with a 70% higher risk of graft failure as compared with live donor kidney transplants. This statistic calls out for living kidney donation from the relatives of patients suffering from chronic renal failure. However, in a study conducted by Christensen, Alan, Raichle, Ehlers and Bertolatus (2002:468-476), findings showed that in spite of the increased risk of graft failure, patients receiving a kidney from a cadaver donor showed modest improvements in quality of life irrespective of the degree of family support, while living donors and recipients who had little family support exhibited increased depression and decreased social functioning after transplantation.

Ideally, every end-stage chronic renal failure patient should have access to dialysis. The reality is that there is not enough money for health-care in the developing world, particularly for expensive and chronic treatment such as renal replacement therapy. There is therefore a need to increase the availability of kidneys for transplantation, especially from living relatives.

Hutchinson (2005:270-277) states that although treatment of chronic renal failure successfully prolongs the survival of patients with kidney disease, it requires that patients cope with frequent deleterious changes in their health and life situation, and

shortened survival. This is very important because poor compliance could result in graft rejection and many other cardiovascular complications. Although the nephrology team is well-equipped to deal with the medical and technical aspects of care, it is less well-equipped to help patients with the impact of the difficult human transitions that come with dialysis and transplant treatment. However, times of great challenge can also be opportunities for personal growth and healing, but this often requires outside support.

Glannon (2008:127-128) argues that kidney transplantation from a living donor currently accounts for 41% of all kidney transplants in the USA. While the percentage is lower in the United Kingdom and other European countries, the number of living donors as compared with cadaver kidney donors will probably continue to increase globally. Glannon (2008:127-128) further argues that kidney transplantation from a living donor is preferable to that from a cadaver donor because of its superior graft survival outcomes.

However, according to Siegel, Alvaro, Lac, Crano and Dominick (2008:80-89), in their study exploring the differences between living and non-living kidney donation (cadaver) among the Hispanics, there are no differences between these two donation formats, but they recommended that further independent studies need to be carried out.

2.5.5 Transplantation versus dialysis

According to White et al (2008:231), the actual procedure and expense of transplantation in theatre tends to be more cost effective than dialysis, with successful transplantation incurring lower costs of treatment and producing better outcomes in terms of quality of life. Transplantation also results in greater ability of patients to participate productively in the community. The financial burden on the management of renal patients will drastically decrease as the treatment of renal transplant patients is actually cheaper than the two other modalities of renal treatment, which are, haemodialysis and peritoneal dialysis.

Meade, Creer and Mahan (2003:165-171) state that as much as transplantation provides the best treatment for chronic renal failure, it subsequently demands the recipients to follow a lifelong medication regimen. The availability of dialysis and transplantation is quite variable in Africa: treatment rates in North Africa are 30 to 186.5 per million population in countries with more established programs: Algeria 78.5; Egypt

129.3; Libya 30; Morocco 55.6; Tunisia 186.5 per million populations (Naicker 2003:119).

The number of patients who have hope of returning to normal health is progressively increasing. As expected, this has increased the government's responsibility to provide dialysis together with the accompanying increasing costs. However, the demand for kidneys exceeds the available supply, so the number of people on the waiting list is steadily increasing.

This gap in supply and demand is actually a global problem and is not specific to South Africa. It is due to a number of problems ranging from a lack of awareness to an increase in diseases such as cancer and HIV/Aids, which exclude people from being eligible to donate. Establishing organ donor and transplant programmes requires that the cultural and organisational challenges to such programmes are recognised.

According to Kaufman, Russ and Shim (2006:81-99), in the ethical field of kidney transplant, live kidney transplantation is one of the techniques linking ethics to intervention and the understanding of the arc of human life to clinical opportunity and consumption. According to Wenger (2004:728-731), a recent consensus statement on the live organ donor noted that "the person who gives consent to be a live organ donor should be competent, willing to donate, free from coercion" and fully informed. This consensus statement does not fully address the potential for surrogates to consent to organ recovery from an incompetent adult, although such clinical circumstances present themselves occasionally.

Orr, Orr, Willis, Holmes and Britton (2007:653-662) argued that research has shown that transplantation improves quality of life for patients with end stage renal disease, although it does not return to pre-kidney failure levels. Kaufman et al (2006:84) explain that the number of kidneys transplanted to people over age 70, both from living and cadaver donors, has increased steadily in the past two decades in the United States. Live kidney donation, on the rise for all age groups, opens up new dimensions of intergenerational relationship and medical responsibility when the transfer of organs is from younger to older people. They further argue that the mediocultural scripting of transplant choice becomes a high stakes obligation in which the long-term impacts on generational relations cannot be foreseen.

Harrington and Kreiss (2008:546-548) stated that because of the growing number of psychiatric patients with renal failure and the increasing availability of renal transplantation as a treatment for chronic renal failure, guidelines directing the use of clozapine in combination with other immunosuppressive therapies are needed.

Smith, Loewenstein, Jepson, Jankovich, Feldman and Ubel (2008:653-658) surveyed kidney transplant patients, both before and after transplants, to establish whether they would overestimate the benefits that a successful transplant had had on their quality of life. Their findings revealed that post-transplant patients recalled their pre-transplant quality of life to be much lower than what they had reported at the time. Consistent with an impact bias, patients substantially overestimated the benefits of a successful kidney transplant, both in terms of predictions of life after treatment, and in their memories of quality of life before the transplant.

2.6 THE HEALTH BELIEF MODEL

Potter and Perry (2005:91) define the health belief model as the relationship between a person's belief and behaviour. This relationship provides the way of clearly understanding how the participants behave in relation to their health and how they comply with health care therapies. The researcher has decided to use this model as it would assist in understanding the factors influencing the relatives' perceptions about kidney donations.

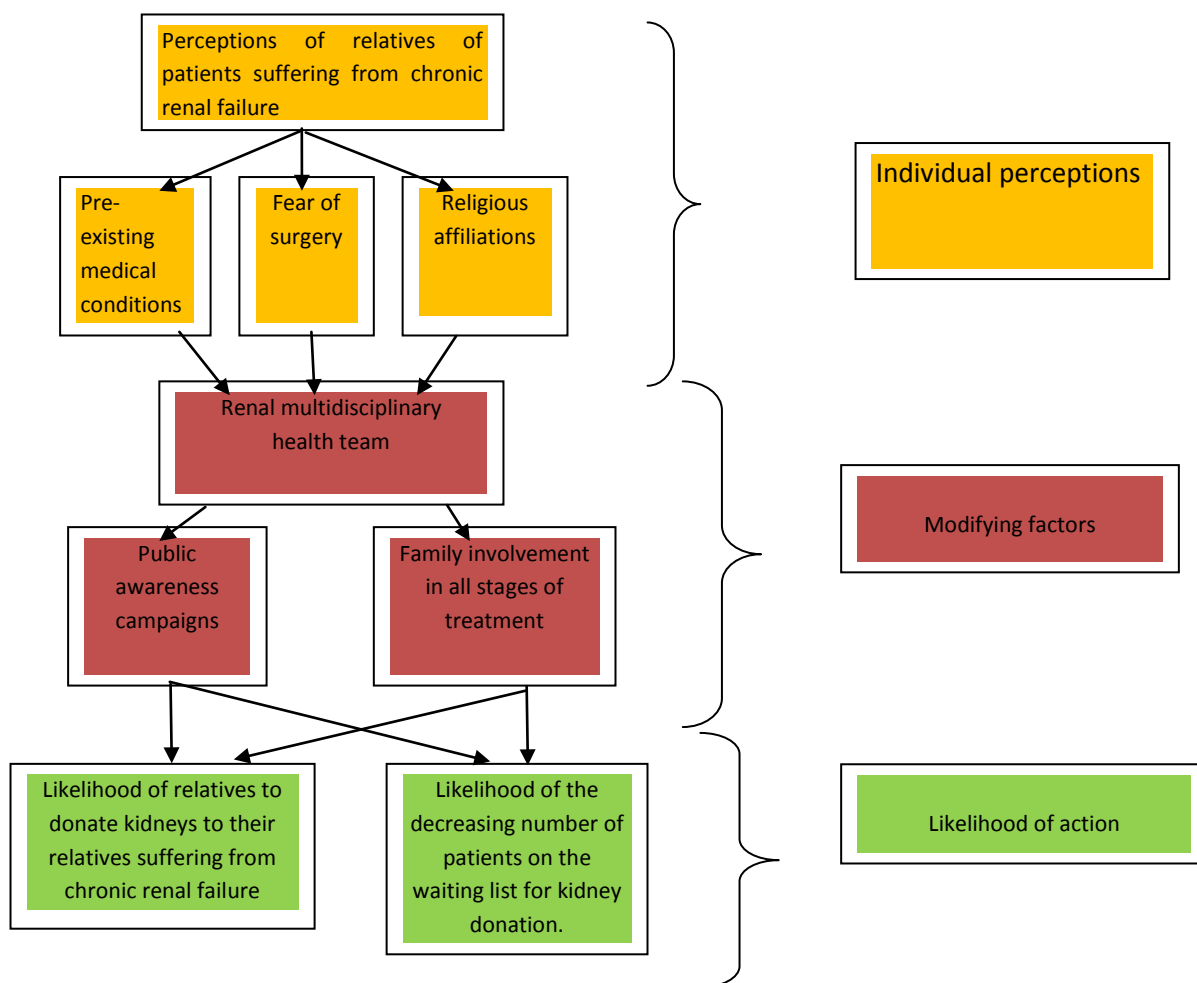


Figure 2.1 Health Belief Model

(Potter & Perry 2005:92)

(Summary of the perceptions of patients suffering from chronic renal failure regarding kidney donation)

This health belief model has three components which include individual's perceptions; modifying factors; and likelihood of action. First of all, the participants must be aware that their relatives are suffering from chronic illness and that one of the modalities of renal therapy is renal transplantation. Secondly, the researcher has to identify that the perceptions of the current treatment of chronic renal failure, which is in their case haemodialysis, has an impact to the patients themselves and their socio-economic status. This perception may be influenced by the perceived threats of chronic renal failure as the debilitating disease. Thirdly, whether the participants will take action regarding

kidney donation to their relatives, will depend on their perceptions thereof. This will then determine their attitude towards kidney donation (Potter & Perry 2005:92).

2.7 PERCEPTIONS TOWARDS KIDNEY DONATION

Boulware, Ratner, Troll, Chaudron, Yeung, Chen, Klein, Hiller and Powe (2005:1671-1680) in their study of attitudes, psychology and risk taking of potential live kidney donors, argue that live donation is a major solution to widening disparities of persons on the waiting lists and rates of persons receiving kidney transplants. Boulware et al (2005:1671-1680) further concluded that the relatives are willing to undergo greater risks of donation as compared to the strangers. The motivation for donation by the relatives ranged from the desires to relieve the suffering of their loved ones to feelings of guilt and ambivalence. Assessment of psychosocial suitability provided important information regarding the importance of thoroughness in obtaining informed consent for kidney donation.

Lennerling et al (2003:1243-1247) identified seven categories of motives for relatives to donate kidneys to their family members suffering from chronic renal failure. These categories are a desire to help; increased self-esteem from doing good deeds; identification with the patient; self-benefit from the relative's improved health; mere logic; external pressure; and a feeling of moral duty.

Both donors and recipients have the same perceptions about the quality of and the emotional relationship and most of them referred to the donation process as being positive, although some had negative emotions and perceptions (Frade, Lopes, Teixeira, Rodriques, Almeida, Dias & Henriques 2011:39-42). The perceptions that patients hold about their illness and treatment appear to be related to the type renal replacement therapy being undertaken. These cognitions have associations with health-related quality of life in dialysis and transplantation that are independent of those of socio-demographic and clinical factors.

Eklarenbach, Vlaicu, Garg, Yang, Clark and Dempster (2006:3) identified the issue of financial risk as a barrier to donation, suggesting that there is also a possibility that donors may be financially disadvantaged by assuming a burden of financial risk through their altruistic act, especially if they have difficulty in receiving unemployment insurance

benefits, out-of-pocket expenses, availability and cost of insurance. For this reason, donors in countries such as Belgium, the United Kingdom, France, Germany, Finland, Hong Kong, Japan, Luxemburg, Netherlands, Poland, Spain, Sweden, Australia and the United States receive reimbursement for directly attributable costs, including expenses and lost wages (Klarenbach et al 2006:3).

Shilling, Norman, Chavin, Hildebrand, Lunsford, Martin, Milton, Smalls and Baliga (2006:838) in their study, "Health Professionals perceptions of the barriers to living donor kidney transplantation among African Americans", identified the following barriers: pre-existing medical conditions; financial concerns; reluctance to ask family members and friends; distrust of the medical community; fear of surgery; and lack of awareness about living donor kidney transplantation.

2.9 CONCLUSION

Warady and Chadha (2007:1999-2009) argue that additional efforts to define the epidemiology of pediatric chronic renal failure worldwide are necessary if a better understanding of the full extent of the problem, areas for study, and the potential impact of intervention is desired.

Provision of knowledge about kidney donation, chronic renal failure, coping skills and all complications thereof, will create an awareness to society as a whole, but especially to health professionals at the primary health care level, where preventive and early diagnostic measures can be applied (Timmers, Thong, Dekker, Boeschoten, Heijmans, Rijken, Weinman & Kaptein 2008:679-690).

CHAPTER 3

RESEARCH DESIGN AND METHOD

3.1 INTRODUCTION

This chapter contains a study of the method and research design used by the researcher. The research methodology refers to the steps, strategies and procedures used for data gathering and analysis in research (Polit & Beck 2008:758). Burns and Grove (2008:223) add that the research methodology is the blueprint for conducting a study and that it is necessary to maximise control over factors influencing the trustworthiness of the findings. This chapter describes the research design and methods used, including the population and sampling frame, data collection, data analysis, trustworthiness and the ethical considerations.

The research design and method facilitated the attainment of the following research objectives to

- explore and describe the perceptions of relatives of patients suffering from chronic renal failure about donating kidneys
- explore and describe the reasons for and against kidney donations
- make recommendations to family members about kidney donation

3.2 RESEARCH SETTING

The study was conducted in the haemodialysis unit of a selected hospital in KwaZulu-Natal, Durban as it is one of the few public hospitals in KwaZulu-Natal that provides haemodialysis to both acute and chronic renal patients. The researcher collected data from 45 relatives who accompanied patients suffering from chronic renal failure to the haemodialysis unit of the hospital.

3.3 RESEARCH DESIGN

A research design is described as a plan or blueprint of how the researcher intends to conduct the research (Babbie & Mouton 2004:55). Research design is a strategic framework for action that serves as a bridge between research questions and the execution or implementation of the research (Blanche, Durrheim & Painter 2008:34). Research methodology focuses on the process, tools and procedure utilised during the research process (Babbie & Mouton 2004:74-75).

This study adopted a qualitative descriptive and exploratory research design to explore and describe the perceptions of kidney donation of the relatives of patients suffering from chronic renal failure regarding kidney donation. The problem statement and research questions supported the selection of a qualitative research design and method, as indicated in the following discussions.

3.3.1 Qualitative design

Qualitative research is especially appropriate to describe and explore the perceptions of the relatives of patients suffering from chronic renal failure regarding kidney donation (Babbie & Mouton 2004:270).

According to Polit and Beck (2008:68), qualitative researchers have a flexible approach to the collection and analysis of data because the researchers do not know ahead of time exactly how the study will proceed. It is, therefore, impossible to define the flow of activities precisely as the flow varies from one study to another.

Many qualitative researchers use the principle of 'data saturation', which occurs when themes and categories in the data become repetitive and redundant, such that no new information can be gleaned by further data collection. Polit and Beck (2008:71) further argue that qualitative researchers must take steps to demonstrate the trustworthiness of the data while in the field. The central feature of these efforts is to confirm that the findings accurately reflect the experiences and viewpoints of the participants, rather than perceptions of the researchers.

Speziale and Carpenter (2007:21) state that qualitative researchers emphasise six significant characteristics in their research: (1) a belief in multiple realities (2) a commitment to identifying an approach to understanding that supports the phenomenon studied (3) a commitment to the participant's viewpoint (4) the conduct of inquiry in a way that limits disruption of the natural context of the phenomena of interest (5) acknowledged participation of the researcher in the research process; and (6) the reporting of the data in a literary style rich with participant commentaries. None of these characteristics presented a problem to the researcher in this study as she has experience in dealing with renal patients and their relatives, and has worked with the staff in the haemodialysis units of different public hospitals.

Speziale and Carpenter (2007:22) further state that qualitative researchers are committed to discovery through the use of multiple ways of understanding. The researcher, while bearing in mind ethical aspects, addressed questions of the study in a way that would be clearly understood by the participants. The discovery leads the choice of method rather than the method leading the discovery. In some cases more than one qualitative approach or more than one data collection strategy may be necessary to fully understand a phenomenon.

In this study the researcher found qualitative design to be compatible with the study because:

- It aims to describe and understand, rather than explaining the human behaviour.
- Due to its interactive and subjective nature, it allows participants to narrate their perceptions, so that human beings can be understood in terms of their uniqueness, holistic nature and dynamic forces (Burns & Grove 2008:23). The researcher in the qualitative paradigm did not attempt to control the context of the research, but has captured the context in its entirety (Brink 2007:11).

Therefore, the qualitative researcher had to make a deliberate attempt to put herself in the shoes of the people she was studying and understand their perceptions, decisions, behavior and practices (Babbie & Mouton 2004:271). Qualitative researchers assume that subjectivity is essential for the understanding of human experience.

3.3.2 Exploratory design

An exploratory design is used “to search for accurate information about the characteristics of particular subjects, groups, institutions or about the frequency of a phenomenon’s occurrence, particularly when little is unknown about the phenomenon” (LoBiondo-Wood & Haber 2006:240). The aim is to gain a broader understanding of a situation, phenomenon or community. In this study, literature was reviewed on the perceptions of relatives of patients suffering from chronic renal failure who need kidney donation. This study then explored and described the perceptions of the relatives.

3.3.3 Descriptive design

LoBiondo-Wood and Haber (2006:240) explain descriptive designs in the health care area as a collection of detailed descriptions of existing variables and the use of data to justify and assess current situations and practices in order to make plans for improving health care practices. Burns and Grove (2008:795) add that descriptive designs are explorative and descriptive of real-life phenomena, where they provide an accurate account of the characteristics of particular individuals, situations and groups.

3.4 RESEARCH METHOD

The research method addresses the development, validation and evaluation of research tools and methods to be used to gather and analyse the information obtained during the study (Polit & Beck 2008:328). Burns and Grove (2008:223) describe the research method as being the entire plan of the study which includes the steps of the research process from problem identification to the actual data collection.

3.4.1 Population and sampling

According to Parahoo (2006:257), a population can be defined as the total number of units from which data can potentially be collected. These units may be individuals, organisations, events or artifacts. A target group is, therefore, the group from which a researcher aims to draw the sample. This population is defined by taking into account how they can be accessed and who can realistically be approached.

Brink (2007:123) defines the “accessible population” as the population which the researcher has access to, as the entire population of the study cannot be easily accessed. The accessible or source population is the aggregate of cases that conform to the designated criteria and who are accessible as subjects for a study (Polit & Beck 2008:338).

The accessible population for this study was the relatives who accompanied patients with chronic renal failure to the haemodialysis unit at the selected hospital. Some of the participants were accessed on their arrival at the haemodialysis unit and some when waiting for their relatives to be taken off the haemodialysis machine. Polit and Beck (2008:55) explain that in a qualitative study, the individuals cooperating in a study play an active rather than a passive role in the research, which is the reason why they are referred to as participants.

3.4.2 Eligibility criteria

Eligibility criteria are the criteria that specify population characteristics. It defines who is included in the population for which the study was designed (Polit & Beck 2008:338). Burns and Grove (2008:366) support this definition by stating that eligibility criteria define who is eligible to become a selected subject and who is not. They further state that eligibility criteria include a list of characteristics essential for eligibility for membership in the target population.

The eligibility criteria for the study participants were:

- Near relatives (parents, sisters, brothers, cousins, nephews, aunts, uncles, etc) who were bringing or collecting patients with chronic renal failure to or from the haemodialysis unit at the selected hospital.
- The relatives of the selected participants have been diagnosed with chronic renal failure, are on haemodialysis and are eligible for a kidney transplant.
- The participants were mostly English and Zulu speaking as this is the common medium of communication in KwaZulu-Natal and the researcher was comfortable with both languages.

3.4.3 Exclusion criteria

Exclusion criteria define the potential participants who will be excluded from the study. The following exclusion criteria were applied for this study:

- Relatives of patients who are on haemodialysis, but who are not eligible for kidney transplant.

3.4.4 Sample

Polit and Beck (2008:239) describe a sample as a subset of population elements and an element as the most basic unit about which information is collected. While the researcher was conducting this qualitative study, she gathered data until the point of saturation was achieved. The sample size was therefore not pre-determined. The proposition that the larger sample is better does not apply in qualitative studies, where the type of sample is usually purposive. Too many participants would cloud the issues and increase the complexity of the analysis process (Brink 2007:136).

During this current study, the researcher purposely selected the participants who complied with the eligibility criteria. Participants were eligible to participate if they were English or Zulu-speaking adults over 18 years of age, able to give consent, and were related to patients who have been diagnosed with renal failure, had been brought in for haemodialysis and were eligible for a kidney transplant. The language criterion was used because the study was conducted in KwaZulu-Natal and most of the patients are illiterate. The researcher, therefore, used the two official languages predominately used in the province. The researcher was comfortable with both languages.

The researcher used purposive sampling to discover ways to obtain accurate, confirmable and meaningful data which reflects the participants' perceptions and insights kidney transplantation.

3.4.5 Sampling and sampling procedure

Polit and Beck (2008:339) describe sampling as the process of selecting a portion of population to represent the entire population so that inferences about the population can be made.

The researcher adopted a non-probability sampling approach and specifically applied the purposive sampling technique. With non-probability sampling, the chances of selection of the participants are not known in advance. Therefore, those who were not available in the research field before the researcher arrived had a zero chance of selection. Again, those who were interviewed were not known prior to the study, and the potential number of all those who were interviewed was also not known. It is acknowledged that the major disadvantage of non-probability sampling is that it does not contribute to generalisation, that the extent of the sampling error cannot be estimated and that bias may be present (Brink 2007:132). When it is not possible to locate the entire population, this type of sampling may represent the population and furthermore, it is more convenient and economical (Brink 2007:131). This means that in this study, the researcher collected data only from those relatives who were available during the data collection period and was primarily concerned about their perceptions, attitudes and values on organ donation. The researcher in this study used purposive sampling, which required the researcher to exercise judgment by selecting the sample on the basis of her own knowledge of the population, its elements and the research purpose (Babbie & Mouton 2004:166).

3.5 DATA COLLECTION

According to Polit and Beck (2008:716), data collection is the “method used to collect information required to conduct the research study”. In this study, the research objectives were accomplished with the collected data (Burns & Grove 2008:50). The researcher used an unstructured self-report method, namely, individual interviews schedules.

Data will be collected by interviewing relatives using an interview schedule, which is a purposefully constructed formal instrument consisting of a set of questions, specifying the wording and order of all questions to be asked of the respondents (Polit & Beck

2008:756). The aim is to collect information/narrative in a consistent manner to gain an understanding of the topic from the perspective of the participants' lived experiences (Charmaz 2006:23). Using an interview schedule helped to limit the researcher's influence on the interview, but allowed for flexibility and probing.

The instrument should have open ended questions to determine specific data (Charmaz 2006:26). The use of well centered questions and conducting a successful interview to allow free flow of information from the participants is the hallmark of conducting an interview. Unstructured data collection tends to gather information, as opposed to structured data collection, which leads to empirical data for testing of hypotheses (Nieswaiadomy 2008:59). Unstructured data collection encourages participants to define and express elements of the phenomenon under scrutiny as they perceive it and often in some order of importance (Polit & Beck 2008:393).

An interview is a directed conversation which is conversational and interactive (Polit & Beck 2008:392). Polit and Beck (2008:324) define unstructured self-report technique as the study where the participants respond to a series of questions posed by the researcher. An unstructured interview is an open interview which allows the participant of the study to speak for him/herself (Babbie & Mouton 2004:289). Unstructured interviews are conversational and interactive, and are the mode of choice when researchers do not have a clear idea of what it is that they do not know (Polit & Beck 2008:392).

The inclusion of the basic questions asked in the interviews and detailing the methodology and environment of the research may enable the study to be replicated to some degree; and the inclusion of excerpts from the interviews will enhance the readers' ability to scrutinise the research for vigor. The disadvantages of interviewing will be counteracted by acknowledging that the results are anticipated to be relevant for that particular set of circumstances. Interviews in this research were conducted using an interview schedule, which consisted of a questionnaire with open-ended questions.

3.5.1 Development of the data collection instrument

According to Burns and Grove (2008:43), data collection is the precise, systematic gathering of information relevant to the research purpose or the specific objectives and

questions of a study. Planning data collection enables the researcher to anticipate problems that are likely to occur and to explore possible solutions. The researcher's qualifications, experience and reflexivity contributed in establishing confidence in the data collected.

Ruane (2008:151) explains that while an unstructured guide may seem like an easy tool to develop, it requires careful thought and work. The researcher formulated an interview guide, which was supplemented with well-placed probes. Probes are questions used to follow up on points mentioned or not mentioned by the respondent. Listing probes on the guide serves to remind the interviewer to pursue important lines of inquiry. Ruane (2008:151) states that unstructured interviewing is very dependent on the participants' willingness to talk in detail, so the researcher had to ensure that the environment for data collection was a warm and supportive "talk" environment.

Speziale and Carpenter (2007:69) argue that during the process of data gathering, researchers plan key interview questions in advance, keep interviews open and discussion-like, verify interpretations by asking more questions and allowing additions and corrections, avoid rhetorical or leading questions, and keep a diary or video tape to facilitate recognition of the researcher's own views during the data analysis process.

The interview guide compiled by the researcher consisted of open-ended questions which enabled the participants to give information until data saturation occurred. The purpose of the questions was to find out their thoughts, perceptions, attitudes, beliefs, feelings, motives, plans, experiences, knowledge levels and memories on various aspects of kidney transplant and kidney donation (Brink 2007:136).

The interview guide comprised the following questions:

1. Do you have any knowledge of or have you heard about chronic renal failure?
2. If the answer to the above question is "yes", what is your understanding of chronic renal failure?
3. Explain how important it is for your relative to come to haemodialysis as scheduled or the consequences of missing haemodialysis sessions.
4. Have you ever heard about kidney donation?
5. If the answer is "yes" what are your perceptions about it?

6. What are your perceptions of kidney donation?

3.5.2 Data collection process

A semi-structured interview was used in this study and the open-ended nature of the questions gave all 45 participants an opportunity to answer the questions according to their own frame of reference.

In this study, extensive field notes were taken during the interviews. Each notes sheet had the interview questions with spaces in between so as to document all the data given. To maintain confidentiality, each sheet of paper was given a code so that the actual names of the participants were not written down. The researcher transcribed all the interviews. The study was conducted from the 6th to the 10th of June 2011 in the haemodialysis unit of the selected hospital. Data was collected in its natural form as the relatives were all in the waiting area and the interviews were conducted in a room nearby so as to ensure privacy.

The researcher conducted 45 in-depth interviews with relatives of patients suffering from chronic renal failure from the 6th to the 10th of June 2011. In this study, the researcher gained the participants' trust by obtaining informed consent from them to participate in the study and by explaining the importance of their participation in ensuring that the data collected was credible. The researcher also assured the participants that she would protect the confidentiality of participants, the information shared and also their anonymity. The participants were advised that the interview would take approximately 15-25 minutes and they were reminded that they could withdraw at any time if they felt uncomfortable with the study.

The interviews were conducted in English and Zulu, but for the purpose of the study, the Zulu interviews were translated into English and transcribed in 'word' format by the researcher. Extensive field notes were taken by the researcher during data collection and were categorised accordingly during data analysis. The researcher practiced time management and answered questions truthfully, and showed interest and enthusiasm during the study. The process of data collection continued until the researcher was assured that data saturation had been achieved.

3.6 DATA ANALYSIS

Data analysis in qualitative research involves examination of words rather than the figures which are considered in quantitative research. It has also been described as a “hands-on process” as the researchers become deeply immersed in the data. In this study, the researcher used the steps of Tech, as described in Creswell (2007:237). When using this type of data analysis, a sequence must be followed so that data is well organised and easily interpreted.

Data analysis is generally not a distinct step in qualitative research studies, but is done concurrently with data collection, unlike quantitative research analysis, which does not begin until all data has been collected. The different forms of qualitative approaches have different types of analysis (Brink 2007:184). In this study, as mentioned, extensive field notes were taken by the researcher during data collection and were categorised accordingly during data analysis.

In general, qualitative data analysis involves three levels of analysis: basic, intermediate and higher. These levels are neither distinct nor linear, but facilitate the process which began during data collection. In this study, the process of data analysis commenced as the researcher broke the data into as many parts or categories as she could identify. She then grouped together some of these parts into manageable themes based on their similarities. The final part of the process was to put the themes together in order to describe the 'whole'. The researcher continually moved backward and forward between these levels or stages, until a comprehensive understanding of the phenomenon as a 'whole' was ready to be reported (Parahoo 2006:393).

Although the semi-structured interviews were centred on the participants' language of choice, the researcher applied accommodation strategies and code switching. Being able to switch from English to Zulu and vice versa helped the researcher and the participants to establish better communication and a closer relationship. Creswell (2007:237) cited that data analysis needs to be done sequentially so that data is well organised and easily interpreted. During data collection, data was so segmented that the researcher had to organise it. To achieve this, the researcher read through the data and started analysing it, using a process of coding. The researcher then described the participants, setting, categories and themes. The next step was to determine how these

categories would be presented, which would assist the researcher in interpreting the meaning of the data.

According to Creswell (2007:155), there are eight steps which the researcher should consider during data analysis: (1) get a sense of the whole (2) pick a document (3) make a list of topics (4) take the list and go back to the data (5) find the most descriptive wording for your topic and turn them into categories (6) make a final decision on the abbreviation of each category and alphabetise these codes (7) assemble the data material belonging to each category in one place and perform a preliminary analysis; and (8) if necessary, record your existing data.

(1) Getting a sense of the whole

The researcher's written notes were analysed systematically through repeated re-reading so as to gain a profound understanding of each interviewer's perceptions. The researcher continually moved backward and forward refining her own analysis and interpretation to ensure validity and reliability of the data collected until a comprehensive understanding of the phenomenon as a 'whole' was ready to be reported.

(2) Picking one document

The search for important themes and concepts began from the moment data collection got underway. Qualitative analysis is labour-intensive, creative and sheer hard work. As the researcher continuously collected data, she was also engaged in formatting the information into a story or picture, which made the process very interesting.

(3) Making a list of topics

According to Polit and Beck (2008:507), the purpose of data analysis is to organise, provide structure to, and elicit meaning from research data. In qualitative studies, data collection and data analysis usually occur simultaneously. The researcher compared and contrasted the text segments identified during data collection looking for regularities and patterns.

(4) Taking the list and going back to the data

The process of data analysis was done inductively so as to allow the categories and patterns to emerge from the data and thereby leading to small and similar data that is more workable (Parahoo 2006:393). The researcher abbreviated the topics as codes, which were then written next to the appropriate segment of the text.

(5) Finding the most descriptive wording for your topics and turn them into categories

Creswell (2007:153) cited that it is very important for the researcher to be comfortable with the process of developing categories and making contrasts and comparisons which will enable her to see contrary or alternative explanations for the findings. The researcher in this study named the categories according to the focus of the study.

(6) Making a final decision on the abbreviation of each category and alphabetising these codes

The coding procedure is the one that is used to reduce the information to themes and categories and this forms the basis for the emerging story to be told by the qualitative researcher.

(7) Assembling the data material belonging to each category in one place and performing a preliminary analysis

The final part of the process was to put the themes together on order to describe the 'whole'. It is important to note that the three levels of analysis: basic, intermediate and higher levels are neither distinct nor linear. All these levels facilitate the process which begun during data collection.

(8) If necessary, recording existing data

The researcher recorded data in the form of notes. Better communication and a closer relationship was established with the participants as the researcher was easily switching from one language to the other. The researcher used the semi-structured interviews

which were centered on the participants' language of choice as some were English-speaking and others Zulu-speaking. The questions asked to the participants helped the researcher to identify the accommodation strategies.

3.7 TRUSTWORTHINESS OF THE STUDY

Polit and Beck (2008:539) suggested the following four criteria for developing the trustworthiness of a qualitative inquiry: credibility, dependability, confirmability, and transferability. These four criteria for trustworthiness represent parallels to the positivists' criteria of internal validity, reliability, objectivity and external validity, respectively.

3.7.1 Credibility

Credibility, an important aspect of trustworthiness, was achieved to the extent that the research methods engender confidence in the truth of the data and in the researcher's interpretations of the data (Polit & Beck 2008:196). The truth, value or believability of the findings is a very important in a study. The researcher's previous knowledge, her clinical experience and literature she consulted also contributed to the credibility of the study. Researcher credibility is also enhanced when research reports describe the researcher's efforts to be self-reflective and to take their own prejudices and perspectives into account.

The researcher is a lecturer who was a nephrology nurse for more than ten years. She has therefore accumulated a wealth of knowledge through her clinical experience, teaching, intensive knowledge about research and thorough literature review. This resulted in the researcher posing meaningful questions based on her knowledge and understanding of the topic. During the study, the researcher used the language preferred by the participant because it was important that they express their views in the language that they are most comfortable with. To enhance credibility, the researcher used data triangulation by using multiple sources of data. The researcher also used multiple literature resources to confirm and enhance her data collection.

3.7.2 Transferability

Transferability or fittingness is the extent to which the findings of a qualitative study can be used by other populations (Polit & Beck 2008:410). Transferability is actually a form of external validity. To enable the reader to judge transferability, the researcher will provide in-depth discussions of the data obtained, data analysis and interpretation of research findings in a research report.

3.7.3 Dependability

Dependability is a further criterion listed by Polit & Beck (2008:410) to establish the trustworthiness of the study. This requires an audit. The inquiry auditor, generally a peer, follows the process and procedures used by the researcher in the study and determines whether they are acceptable, that is, dependable (Brink 2007:119).

3.7.4 Confirmability

Confirmability is similar to objectivity in that it is the degree to which study results are derived from characteristics of participants and the study context, not from researcher biases. In the present research, the researcher sought confirmation from the informants that her interpretations were truly a reflection of their cultural perspectives in kidney donation.

Confirmability guarantees that the findings, conclusions and recommendations are supported by the data and that there is an internal agreement between the investigator's interpretation and the actual evidence (Brink 2007:119).

3.8 CONCLUSION

The research design, research populations, methodology for data collection and how data was analysed were described in this chapter. The research findings and interpretation will be discussed in chapter 4.

CHAPTER 4

ANALYSIS, PRESENTATION AND DESCRIPTION OF RESEARCH FINDINGS

4.1 INTRODUCTION

The previous chapter described the methodology of this study. The focus of this chapter is on the presentation and description of results. The purpose of the study was to explore and describe the perceptions of relatives of patients with chronic renal failure regarding kidney donation.

The objectives of the study were:

- explore and describe the perceptions of relatives of patients suffering from chronic renal failure about donating kidneys
- explore and describe the reasons for and against kidney donations
- make recommendations to family members about kidney donation

The study was designed to answer the following research question:

What are the perceptions of the relatives of patients suffering from chronic renal failure regarding kidney donation?

4.2 SAMPLE CHARACTERISTICS

Polit and Beck (2008:339) describe a sample as a subset of population elements and an element as the most basic unit about which information is collected. The researcher collected data from the relatives of the patients suffering from chronic renal failure who were bringing patients to the Haemodialysis Unit at Addington Hospital for haemodialysis and also from those who were collecting patients from unit. The participants were approached by the researcher while waiting in the designated waiting area for the relatives. During this current study, the researcher purposely selected the

participants who complied with the eligibility criteria. Participants were eligible to participate if they were English or Zulu-speaking adults over 18 years of age, able to give consent, and were related to the patients brought for haemodialysis. KwaZulu-Natal is a multi-cultural society and the sample was composed of Africans, Asians and Coloureds. Most of the participants were Christian, but there were also Muslims, Hindus and some belonging to the Shembe religion. The researcher used purposive sampling to discover ways to obtain accurate, confirmable and meaningful data to reflect the participants' perceptions and insights about living kidney donation.

While the researcher was conducting a qualitative study, she gathered data until the point of saturation was achieved. The sample size was therefore not pre-determined. The proposition that a larger sample is better does not apply in qualitative studies, where the type of sample is usually purposive. Too many subjects would cloud the issues and increase the complexity of the analysis process (Brink 2007:136).

4.3 DATA MANAGEMENT AND ANALYSIS

When a qualitative researcher embarks on data analysis, it is very important to ensure that the collected data is well managed and efficiently organised. Data management and analysis clearly stipulates how qualitative data will be transcribed, coded and organised.

4.3.1 Data management

A semi-structured interview was used in this study and the open-ended nature of questions gave the participants an opportunity to answer the questions according to their own frame of reference. In this study, extensive field notes were taken during the interview. Each notes sheet had the interview questions and spaces in between so as to document all the data given. Each sheet of paper was given a code as the actual names of the participants were not written to maintain confidentiality. The researcher transcribed all the interviews.

Creswell (2007:237) cited that data analysis needs to be done sequentially so that data is well organised and easily interpreted. During data collection, data was so segmented that the researcher had to reorganise it so that it could be seen as a whole. To achieve

this, the researcher had to read through the data and start analysing it with a coding process. The researcher then described participants, setting, categories and themes

4.3.2 Data analysis

Unlike quantitative research analysis, which does not begin until all data has been collected, in qualitative research studies data analysis is generally not a distinct step, but is done concurrently with data collection. The different forms of qualitative approaches have different processes of analysis (Brink 2007:184). In this study, as mentioned, data was recorded on an audio-tape and transcribed by the researcher.

The researcher used the following steps of qualitative data analysis sequentially for easy interpretation (Creswell 2007:237).

(1) Getting a sense of the whole

The researcher's written notes were analysed systematically through repeated re-reading so as to gain a profound understanding of each interviewer's perceptions. The researcher continually moved backward and forward refining her own analysis and interpretation to ensure validity and reliability of the data collected until a comprehensive understanding of the phenomenon as a 'whole' was ready to be reported.

(2) Picking one document

The search for important themes and concepts began from the moment data collection got underway. Qualitative analysis is labour-intensive, creative and sheer hard work. As the researcher continuously collected data, she was also engaged in formatting the information into a story or picture, which made the process very interesting.

(3) Making a list of topics

According to Polit and Beck (2008:507), the purpose of data analysis is to organise, provide structure to, and elicit meaning from research data. In qualitative studies, data collection and data analysis usually occur simultaneously. The researcher compared and contrasted the text segments identified during data collection looking for regularities

and patterns.

(4) Taking the list and going back to the data

The process of data analysis was done inductively so as to allow the categories and patterns to emerge from the data and thereby leading to small and similar data that is more workable (Parahoo 2006:393). The researcher abbreviated the topics as codes, which were then written next to the appropriate segment of the text.

(5) Finding the most descriptive wording for your topics and turn them into categories

Creswell (2007:153) cited that it is very important for the researcher to be comfortable with the process of developing categories and making contrasts and comparisons which will enable her to see contrary or alternative explanations for the findings. The researcher in this study named the categories according to the focus of the study.

(6) Making a final decision on the abbreviation of each category and alphabetising these codes

The coding procedure is the one that is used to reduce the information to themes and categories and this forms the basis for the emerging story to be told by the qualitative researcher.

(7) Assembling the data material belonging to each category in one place and performing a preliminary analysis

The final part of the process was to put the themes together in order to describe the 'whole'. It is important to note that the three levels of analysis: basic, intermediate and higher levels are neither distinct nor linear. All these levels facilitate the process which began during data collection.

(8) If necessary, recording existing data

The researcher recorded data in the form of notes. Better communication and a closer relationship were established with the participants as the researcher was easily switching from one language to the other. The researcher used the semi-structured

interviews which were centered on the participants' language of choice as some were English-speaking and others Zulu-speaking. The questions asked to the participants helped the researcher to identify the accommodation strategies.

The process of data analysis continued as the researcher started breaking the data into the six categories she had identified. This was followed by grouping together some of these parts into manageable themes based on their similarities. The final part of the process was putting the themes together in order to describe the 'whole'. Once the data had been interpreted, the next step was to determine how these categories would be presented to give the meaning of the data collected.

4.4 RESEARCH RESULTS

The findings of the study revealed that most of the relatives of patients suffering from chronic renal failure were aware of kidney donation, but were afraid to come forward for kidney donation due to existing medical conditions and fear of living with only one kidney. Tables 4.1 to Table 4.6 below present the categories and sub-categories that emerged.

4.4.1 Theme 1: Participants' basic knowledge of understanding of chronic renal failure

Table 4.1 Participants' basic knowledge of understanding of chronic renal failure

THEME 1	CATEGORIES	SUB-CATEGORIES
Participants' basic knowledge of understanding of chronic renal failure	The relatives verbalised basic knowledge or general understanding of chronic renal failure	<p>Chronic renal failure is when the kidneys fail to function normally resulting in inability to pass urine</p> <p>Chronic renal failure is the disease that affects the kidneys</p> <p>Chronic renal failure is when the body depends on haemodialysis in order to survive</p>

To establish the basic knowledge of participants regarding chronic renal failure, the first thing the researcher asked them was to tell her what they understand about chronic

renal failure. Whilst bearing in mind that they would use simple terms, this question allowed the participants to elaborate on their general understanding of chronic renal failure and what it entails. The finding revealed that, generally, participants had a good understanding of chronic renal failure and some of them even gave the causes, signs and symptoms of the condition. Three sub categories emerged in relation to this theme.

4.4.1.1 Sub-category 1: Chronic renal failure is when the kidneys fail to function normally resulting in inability to pass urine

“This is the condition when your kidneys are not functioning and therefore not passing urine but only depending on the haemodialysis machines to clean your body.”

Berman et al (2010:1310) argue that oliguria or anuria also indicate the impairment of blood flow to the kidneys or impaired renal functioning which need to be treated promptly as it can result into chronic renal failure.

4.4.1.2 Sub-category 2: Chronic renal failure is the disease that affects the kidneys

Some participants cited that

“chronic renal failure is the disease that affects the kidneys”,

but the most simple explanation was that:

“chronic renal failure is the disease that affects the whole body because of the kidneys that cannot work.”

Life threatening uraemia can be identified by anorexia, lethargy, confusion and coma. Other signs and symptoms include nausea, vomiting, shortness of breath and seizures (Meyer et al 2007:1316-1325).

4.4.1.3 Sub-category 3: Chronic renal failure is when the body depends on haemodialysis in order to survive

According to one of the participants:

“This is the condition when your kidneys are not functioning and only depend on the haemodialysis machines to clean your body.”

White et al (2008:229-237) explain that chronic renal failure is the stage when the patient is completely dependent on some form of dialysis or kidney transplant in order to survive.

4.4.2 Theme 2: Participants’ awareness of the consequences of missing haemodialysis sessions

Table 4.2 Participants’ awareness of the consequences of missing haemodialysis sessions

THEME 2	CATEGORIES	SUB-CATEGORIES
Participants’ awareness of the consequences of missing haemodialysis sessions	Awareness of the consequences of missing haemodialysis sessions	<p>Patients who miss their haemodialysis treatment experience difficulty in breathing</p> <p>Patients cannot miss any sessions as the haemodialysis unit is closed after hours</p>

Two sub-categories emerged from the data. According to Hanly (2007:59-66), haemodialysis may further increase the considerable cardiovascular morbidity and mortality in this patient population. The researcher wanted to find out from the participants if they knew the importance of complying with the scheduled haemodialysis dates. She therefore asked participants to explain how important it is for their relatives to come for haemodialysis as scheduled.

4.4.2.1 Sub-category 1: Patients who miss their haemodialysis treatment experience difficulty in breathing

One participant stated:

“My son once missed haemodialysis session because of taxi strike in Durban and was “ok” the whole day but could not sleep at night because of difficulty in breathing. He was rushed to hospital at night and the haemodialysis sister who

was on call that arrived to dialyse him and he was so much better afterwards. I made an oath that he will never miss haemodialysis again”.

It was very interesting to establish that all the participants knew the importance of coming for haemodialysis and some of them elaborated on this question. Haemodialysis compliance was covered by some of the participants as they answered the question of the importance of haemodialysis, as mentioned in theme 2.

4.4.2.2 Sub-category 2: Patients cannot miss any sessions as the haemodialysis unit is closed after hours

The researcher also wanted to establish whether participants were aware of the consequences of patients missing their haemodialysis sessions.

“I will make sure that my son does not miss any session as the haemodialysis unit is closed after hours”.

The findings revealed that most participants were aware of the fact that the haemodialysis unit is closed after hours and that patients should not miss their scheduled haemodialysis sessions as they would not be able to come to the unit in an emergency. Few participants were not clear of the consequences of missing haemodialysis sessions. Hutchinson (2005:270-277) states that as much as renal replacement therapies successfully prolong the survival of patients with kidney disease, patients have to cope with frequent changes in their health and life situation, and shortened survival.

4.4.3 Theme 3: Participants’ awareness of kidney donation

Table 4.3 Participants’ awareness of kidney donation

THEME 3	CATEGORIES	SUB-CATEGORIES
Participants’ awareness of kidney donation	Transplant awareness	Relatives had heard about kidney donation from the patients, the renal team and the media

The question in the interview guide leading to theme 3 was, “Have you ever heard about kidney donation?” One sub-category emerged in relation to this theme. Lennerling et al (2003:1243-1247) explain that organ donation criteria has expanded as compared to

early years where only parents and siblings were accepted, as it now includes cousins, uncles, aunts, spouses and close friends. This has contributed to the increase awareness of transplantation as the better renal replacement therapy.

4.4.3.1 Sub-category 1: Relatives had heard about kidney donation from the patients, the renal team and the media

The researcher noted with interest that all the participants had heard about kidney donation, not only from the patients and renal team, but also from the media. The participants also mentioned that their relatives with chronic renal failure would sometimes ask them (participant) how they feel about organ donation and if they want to come forward to be worked-up for transplantation. Boulware et al (2005:1671-1680) concluded that the relatives are willing to undergo greater risks of donation as compared to the strangers, as they are being motivated by the desire to relieve the suffering of their loved ones.

“When my husband was diagnosed with chronic renal failure, the renal doctor talked to us as immediate family since we asked for explanation regarding his progress. After that we even noted in the media that there are kidneys awareness days.”

4.4.4 Theme 4: Participants’ views/perceptions about kidney donation

To establish the participants’ perceptions about kidney donation the researcher asked, “What are your views or perceptions about kidney donation?” This was the main question of the study as the researcher wished to obtain in-depth information on the perceptions of the relatives of patients suffering from chronic renal failure. This study revealed that while most of the individuals had positive perceptions towards kidney donation, participants seemed reluctant to come forward to donate a kidney and gave various reasons why they could not do so.

Table 4.4 Participants' views/perceptions about kidney donation

THEME 4	CATEGORIES	SUB-CATEGORIES
Participants' views/perceptions about kidney donation	Transplant acceptance	Pre-existing medical conditions decrease the chances of getting donors Fear of surviving with one kidney Participants failing some investigation for donor work-up and thereby not continuing with the preparation for kidney donation

Participants identified three sub-categories in this theme.

4.4.4.1 *Sub-category 1: Pre-existing medical conditions decrease the chances of getting donors*

According to Shilling et al (2006:220), in their study of perceived barriers to living kidney donation among African Americans in Northern Carolina, the barriers that were identified were: pre-existing medical conditions; financial concerns; reluctance to ask family members and friends; distrust of the medical community; fear of surgery; and lack of awareness about living donor kidney transplantation, particularly with those who are less educated and living in rural areas. In this study, the researcher identified that pre-existing medical conditions such as diabetes mellitus and high blood pressure were also the main barrier to living kidney donation and that conditions were prevalent in most of the families. Even although most of the participants were positive towards kidney donation, the pre-existing medical conditions play a major role in the escalating number of patients waiting for kidney transplant.

"Kidney donation is a good thing but the problem is that I'm diabetic and my daughters are both very young to donate (under the age of 18 years)."

"I'm too old to donate and my niece is diabetic, so if anyone who is a guardian angel can donate, that will really be appreciated."

"I am willing to donate but the problem is that I have high blood pressure and the doctor also said that I'm overweight."

"Kidney donation is a good thing but I've never taken it serious since my brother is doing well on haemodialysis."

In this last instance, the researcher had to use her expertise and previous experience to explain to the participant the modalities of renal replacement therapy and kidney donation as the treatment of choice.

4.4.4.2 Sub-category 2: Fear of surviving with one kidney

In this study, the researcher established that some participants are scared to donate because they think that living with one kidney might cause complications to them.

“It is a very sensitive issue which is even difficult to start discussing and I feel sorry for my husband. I’m personally very scared of donating. What if I also become ill or what if my one and only son become ill and also needs a kidney? I think we must rather wait for donation from the unknown person.”

“I can only donate to my parents and my kids but not my husband as he can divorce me and take another woman forgetting that he’s surviving because of my kidney transplanted to him.”

Some of the participants expressed the feeling of fear of surgery asking questions such as:

“Is it possible to bear children after kidney donation?”

“How long does it take to recover after kidney donation?”

The above questions made it clear that there is also fear of surgery. Crombie and Franklin (2006:198) in their study of family issues implicit in living donation, discussed family relationships, complexities of seeking a donor from within the family, gift reciprocity, donor moral constraints and difficulties encountered by the donor during the decision making process. Humanity was the primary motivation for those willing to donate.

4.4.4.3 Sub-category 3: Participants failing some investigation for donor work-up and thereby not continuing with the preparation for kidney donation

The donor needs an intensive screening to be done. This includes a series of laboratory and X-ray tests.

“Both my daughters were interested to donate for their only brother; one was excluded at the early stages of the investigations because of the heart problem that was identified. With the younger daughter, it was detected that the blood supply to her own kidney is not good and is currently being investigated for that.”

Some of the participants commence the renal transplant workup programme, but because of different investigations that are done in the process, they end up being disqualified as potential kidney donors. This becomes another burden to the family because it is difficult to get a matching donor.

Screening is done for kidneys (urinary testing and CT angiogram) and liver functioning, heart diseases, lung diseases as well as past exposure to viral illness. These tests are done in the hospital at an out-patient basis to ensure medical clearance for pre-existing conditions. It is very important that the donor and the recipient be histocompatible, thereby minimising genetic disparity. This is ensured by doing the blood grouping (ABO) and tissue typing (Human Leukocyte Antigen [HLA]) (Yang 2007:1542-1551).

4.4.5 Theme 5: Participants’ religious influence on kidney donation

Ismail, Massey, Luchtenburg, Claasens, Zuidema, Busscbach and Weimar (2011:141-144), in their study of religious attitudes towards living kidney donation among Dutch renal patients, observed that although many religions such as Islam, Christianity, and Buddhism believe that religion promotes helping others and also saving lives, there are still uncertainties and lack of awareness about the position of religion regarding kidney donation. These authors further argue that there are certain religious objections to the concept of organ transplant, the main one being that the body must enter the grave “whole”. This belief was mostly stressed by Turkish and Moroccan patients in their study.

The question that was posed by the researcher to find what effect religion might have on kidney donation and leading to this theme was, “How is organ donation, and especially kidney donation, viewed according to your own religion?”

Table 4.5 Participants' religious influence on kidney donation

THEME 5	CATEGORIES	SUB-CATEGORIES
Participants' religious influence on kidney donation	Religious influence on kidney donation	<p>Some religious denominations accept kidney donation</p> <p>Some participants are not aware of any religious influence in kidney donation</p> <p>Any organ donation is religiously taken as "the gift of life"</p> <p>Islamic religion views kidney donation as the means of alleviating pain and saving life</p> <p>Participants' fear of not being accepted by the ancestors if not buried as "whole"</p>

Five sub-categories emerged that are related to this theme.

4.4.5.1 Sub-category 1: Some religious denominations accept kidney donation

Oliver, Woywodt, Ahmed and Saif (2011:1745) stated that most religious denominations support organ donation, but it is up to an individual to donate to a fellow patient whose life depend on them to be transplanted and get another chance of life.

"Kidney donation is well accepted by Christianity but it is up to an individual on how he/she feels about it. My family comes first, if there anything I could do to save my only grandchild, I would do it."

"My sister was donated a kidney before, but from unknown person, there were no problems with our religion, but instead, everyone was praying for her speedy recovery. Therefore, I assume that kidney donation is fully supported by our religion (Zion Christian Church)."

Most of the participants in the study revealed that their religions are not against kidney donation at all, but it became evident that there is a big gab of knowledge that needs to be filled up by the health care providers.

4.4.5.2 Sub-category 2: Some participants are not aware of any religious influence in kidney donation

“Kidney donation has not been discussed by anyone in our church but I don’t think it can be a problem since it is just a “gift of life.”

The researcher concluded that even if kidney donation is not discussed in some religious affiliations, it does not mean that it is against the constitution of the church to donate organs. Ismail et al (2011:221) in their study of “Religious attitudes towards living kidney donation among Dutch renal patients” observed that there are still uncertainties about the position of religion as well as the lack of awareness within communities due to the varying interpretations of the Holy Scripture as well as misconceptions on kidney donation.

4.4.5.3 Sub-category 3: Any organ donation is religiously taken as “the gift of life”

In this study the researcher discovered that some religions such as Christianity and Islam encourage the living donation of organs and the participants all shared a common perception that “it is just a gift of life”.

As much as there are still uncertainties and lack of awareness regarding the position of religion in organ donation, various religions are in favour of organ donation and this promotes positive attitude towards helping others and saving someone’s life where possible (Oliver et al 2011:1745).

4.4.5.4 Sub-category 4: Islamic religion views kidney donation as the means of alleviating pain and saving life

One of the Islamic relatives said:

“My religion regards organ donation as means of saving life and is completely accepted.”

Ismail et al (2011:141-144) stated that the main purpose of kidney donation is “to save life” and promoted living donation. According to these authors, Islam, Christianity and

Buddhism do not prohibit giving and receiving of living or deceased organs. In this current study, although the participants were from various cultural and religious backgrounds, most of them verbalised that their religions are in great support of living organ donation. The findings revealed that a common perception of organ donation was that it is “the gift of life”.

4.4.5.5 Sub-category 5: Participants’ fear of not being accepted by the ancestors if not buried as “whole”

In contrast, however, it was noted in this study that few participants, who were from the Shembe denomination, felt that kidney donation was against their religious belief as they believed that the body should enter the grave “whole”.

“My ancestors will not accept me in my family when I die because I would not be the “whole” if I donate my kidney.”

This finding was in support of the findings of Ismail et al (2011:143) who cited that Turkish and Moroccans also believe that their ancestors will not accept them if they enter the grave not being “whole”. Traditional cultural beliefs like entering the next world as a whole were acknowledged by the researcher.

4.4.6 Theme 6: Participants’ Initial health services sought by the patient

According to Berman et al (2012:68), when individuals enter the second stage of health and illness, which is the assumption of a sick role, the medical assistance they seek is dependent on their health beliefs and practices. Some may seek treatment from a health care provider, while others may just rely on over-the-counter medications. The researcher, wishing to establish what initial treatment the patients had sought, asked the participants, “What health care did you seek for the kidney problem of your relative?”

Table 4.6 Participants' initial health services sought by the patient

THEME 6	CATEGORY	SUB-CATEGORIES
Participants' initial health services sought	Initial health services provided for the patient	Family doctor or local clinic followed by referral to hospital. Initial use of home remedies followed by seeking professional advice. Initial use of herbal medication given by witchdoctors followed by seeking professional advice.

Three sub-categories were identified.

4.4.6.1 Sub-category 1: Family doctor or local clinic followed by referral to hospital

It is interesting to note that most of the participants verbalised their relative had initially consulted a general practitioner or had been to the nearest primary health care centre, and were then referred them to the hospital where chronic renal failure was diagnosed.

"I took my husband to the general practitioner but when the condition worsened, he had to be rushed to the hospital where he was diagnosed with chronic renal failure."

According to Andrews (2008:257), it is cited that a thorough monitoring of the patients in primary health care will enable the patients who develop a more severe form of renal failure to be detected at an earlier stage.

4.4.6.2 Sub-category 2: Initial use of home remedies followed by seeking professional advice

Some participants stated that they had first attempted to use over-the- counter medication, but when it did not help, they had sought professional advice.

"My sister used home remedies which did not help at all and thereafter started to use over-the-counter medication. After using over-the-counter medication for a long time, the condition worsened and was taken to hospital."

The continuous use of over-the-counter medication is associated with the faster progression of renal failure and an increased risk of reaching the stage of chronic renal failure (Broe & Elseviers 2009:2101).

4.4.6.3 Sub-category 3: Initial use of herbal medication given by witchdoctors, followed by seeking professional advice

In contrast, the researcher established that few participants had a strong belief in herbal medication and had initially turned to traditional healers and sangomas for medication. However, when there was no improvement, they sought professional advice.

“I really believed that my dad was bewitched as he could not point any specific area that was sore. The family then decided to first take him to the sangoma but unfortunately the condition worsened and was brought to hospital two weeks later”.

Connors and Altshuler (2009:14) argue that herbal medications are much easier on the body and can be used for more than one condition, as opposed to pharmaceutical counterparts.

4.5 OVERVIEW OF RESEARCH FINDINGS

The researcher established that most of the participants were very knowledgeable about chronic renal failure and the consequences of poor compliance to haemodialysis. This implies that patients and relatives have been fully informed by the renal nurses and the multidisciplinary team about chronic renal failure, its treatment modalities and kidney donation. It is evident that this team works very hard on different strategies to educate the community at large on kidney donation in order to save people's lives.

Although participants had been fully informed about kidney donation and transplant, the findings showed that most of them were reluctant to become part of the programme themselves and donate a kidney. This was identified to be the most important result of the study. However, those whose religion was positive towards organ donation might be keen to be worked-up for kidney donation. Oliver et al (2011:1745) stated that as much as most religious denominations support organ donation, it is up to an individual to donate to a fellow patient whose life depend on them to be transplanted and get another chance of life.

It is noteworthy that many individuals have positive perceptions towards kidney donation, but because of medical conditions and being scared of living with one kidney, the thought of personally donating a kidney caused psychological discomfort because they found it disturbing and threatening. The family or relatives of the patients with chronic renal failure need time to work through their reactions and feelings about kidney donation at an earlier stage of their relatives' condition, before the situation becomes critical, so that they can deal with these negative perceptions. Increased self-esteem from doing good deeds is amongst the seven identified categories of motives for relatives to donate kidneys to their family members suffering from chronic renal failure (Lennerling et al 2003:1243-1247).

4.6 CONCLUSION

Cronin (2008:130) cited that global shortage of organs for transplantation means that there are thousands of people dying unnecessarily every year. This is taken as an unacceptable loss of human life as saving a life is one of the most important things that one individual can do for another. It is therefore important to promote strategies to save human life prevent human suffering. However, it is equally important that these strategies are promoted within acceptable moral limits and follow ethical guidelines.

The researcher concluded that participants' religious beliefs and overall knowledge influence their perceptions towards kidney donation. It is interesting to note that the community at large needs intensive awareness programmes on kidney donation to be initiated by the government working harmoniously with the renal multidisciplinary health team as well as the non-governmental organisations. The need for living kidney donation is increasing drastically and this has major quality of life implications to both the recipients and the donor (Crombie & Franklin 2006:199).

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

It is again vital for the researcher to mention that the purpose of the study was to explore and describe the perceptions of the relatives of patients suffering from chronic renal failure regarding kidney donation. Chapter 4 presents the research findings of the study and describes the perceptions of the relatives of patients suffering from chronic renal failure regarding kidney donation. In this chapter, the researcher focuses mainly on the conclusions and recommendations based on what was discussed in the previous chapter.

The study aimed at addressing the following research question.

What are the perceptions of the relatives of patients suffering from chronic renal failure regarding kidney donation?

The research design and method facilitated the attainment of the following research objectives:

- To explore and describe the perceptions of the relatives of patients suffering from chronic renal failure regarding kidney donation.
- To explore and describe the reasons for and against kidney donations
- To make recommendations to family members about kidney donation

The conclusions are derived from the perceptions of the relatives of patients suffering from chronic renal failure regarding kidney donation based on the purpose, research questions and the results of the study. The recommendations are based on the conclusions and the purpose of the study.

5.2 SUMMARY AND INTERPRETATION OF THE RESEARCH FINDINGS

This section of the research study summarises the findings based on the research objectives. The first question of the interview guide related to participants' basic understanding of chronic renal failure and this was established by the researcher asking the question, "What do you understand about chronic renal failure?" It became clear from the findings that the majority of the participants were fairly knowledgeable about the subject and that only a small percentage knew nothing at all about it. Participants had a very good basic knowledge of renal failure as some even quoted the signs and symptoms and lifestyle changes, such as dietary restrictions. It is also noted that some of the participants were unsure of all the aspects of chronic renal failure and needed some clarification regarding some concepts of the condition and some of physiological changes that it brought about. In contrast, the researcher established that there are participants who do not know anything at all about chronic renal failure and need intensive explanation and some form of guidance and referral to relevant health professional for further assistance. What became clear was that most of the participants had acquired a lot of knowledge and understanding of chronic renal failure by becoming involved in the support and care of their beloved ones.

Bhengu and Uys (2004:24) cited that the lack of information and knowledge about organ donation and kidney transplantation among the Zulu-speaking people is greatly related to their traditional Zulu beliefs about their values, social structure, life patterns, death, burial and life thereafter.

Haemodialysis compliance was specifically intended to find out if the participants know the consequences of missing haemodialysis. In this study the researcher concluded that all the participants being studied knew the importance of haemodialysis (n=45). These results made it clear that the relatives really understood why the patients have to come for haemodialysis on scheduled dates and times. It is interesting to note that most of the participants were aware of the consequences of missing the scheduled haemodialysis appointments and explained to the researcher that their relatives accumulated toxins and waste which could not be excreted in any form except haemodialysis and that because the unit is not available after normal office hours, the facility might not be available to provide the treatment in an emergency. The reality of the situation is that delays in being haemodialysed can result in loss of human life. This delay is caused by

the fact that while the unit is fully functional during the day, most of the nurses stay out of the hospital premises and need to be fetched from home when they are on call. Only few participants were not aware of the serious consequences of missing the scheduled haemodialysis treatments and they were relatives of patients who had been newly diagnosed with chronic renal failure and were still in the process of being prepared for the chronic renal transplant programme.

The researcher obtained the interesting finding that all the participants knew about kidney donation as they have heard about it from their relatives, renal health team and media. As all the participants were aware of kidney transplant or donation, these results are challenging to the renal multi-disciplinary health team as it is so obvious that they need to embark on intensive awareness programmes so that the society at large will develop that intrinsic acceptance of the concept of kidney donation.

Although all the study participants were aware of kidney donation as discussed in transplant awareness, the results revealed that some of them had positive perceptions towards kidney donation, while others had negative perceptions. These findings emphasise the fact that as much as people are aware of kidney donation, they need to be intensively informed or educated on kidney transplantation so as to take it positively. As discussed above, the renal multi-disciplinary health team, the government, as well as non-governmental organisations need to be actively involved and formulate the policies which will bring about change to the society as a whole. It is therefore concluded that the provision of knowledge about kidney donation, chronic renal failure, coping skills and all complications thereof, will create an awareness to society as a whole, especially to health professionals at the primary health care level, where preventive and early diagnostic measures can be applied (Timmers et al 2008:679-690).

In this study the researcher established that participants' religious affiliation played a major role in influencing their perception on kidney transplantation. Those participants whose religion was positive towards transplantation were more open to the idea of assisting their relatives by kidney donation. Some of the participants in this were unsure of their religious perceptions and only a few insisted that their religion was completely against organ donation because of the belief that they need to be buried "whole". This is a challenge to health professionals in that as much as they emphasise the importance

of kidney donation, they have to respect the individual's religious beliefs and cultural values.

As indicated in chapter 4, there are those participants who indicated that their relatives suffering from chronic renal failure had initially contacted health professional (general practitioners, clinics, hospitals), some verbalised that their relatives with chronic renal failure had initially used home remedies, but had sought professional assistance when these were not helpful. The researcher also established that there are few participants who had first consulted sangomas or traditional healers for assistance before they had opted for medical assistance.

The fact that most of the study population's relatives had initially gone directly to health professionals indicated the importance of health care providers being educated through seminars, conferences or workshops about the prevention of chronic renal failure, early detection, proper management during the acute stage of renal failure and lastly early referral to prevent complications. This includes proper management of diseases that contribute to chronic renal failure like diabetes mellitus and hypertension.

5.3 RECOMMENDATIONS

Based on the findings, these are the recommendations that are made on the Department of Health, nursing management and further research:

5.3.1 Department of Health

The observation of the current situation suggests that the cost incurred by haemodialysis sessions can be cut down dramatically if organ donors could be made available, and this is the significance of this study.

There is a great need to improve the pool of the potential kidney donors for better health care delivery in our country. Public education programmes should be encouraged to put more emphasis on the management of some of the etiological diseases of chronic renal failure such as diabetes mellitus and hypertension.

5.3.2 Nursing management

Establishing organ donor and transplant programmes requires that the organisational and cultural challenges to such programmes be recognised and addressed accordingly (White et al 2008:170). With respect to the findings of this study, all the outlined deficiencies need to be addressed so as to improve the donor rate in South Africa.

5.3.3 Further research

Since this study was limited to only the relatives of patients attending haemodialysis in one selected hospital, the results cannot be generalised to all South Africans. It is therefore recommended that future studies may be done in other provinces of South Africa or other countries in sub-Saharan Africa on the following topics:

- Perceptions of patients on peritoneal dialysis regarding kidney donation.
- The role played by the transplant coordinator in dealing with the long waiting list for patients awaiting kidney donation.

5.3.4 Contribution of the study

This study has enabled the researcher to explore and describe the perceptions of relatives of patients suffering from chronic renal failure regarding kidney donation. During the course of the study the researcher explored the reasons for and against kidney donation. With some of the participants, the researcher had to use her expertise and competence in the renal field by explaining and making recommendations about kidney donation.

The researcher has embarked on a major study which gave a picture of the perceptions of relatives of patients suffering from chronic renal failure regarding kidney donation. The findings or the results discussed in chapter 4 will be useful to the professionals, especially the Renal Multidisciplinary team which includes the Social workers, Dietician, Psychologists, Nephrologists and the renal nurses, working with chronic renal failure patients and communicating directly with their relatives.

The health care professionals will get a better understanding of the feelings and or perceptions of the relatives and will therefore embark on the awareness programmes as well as thorough one-to-one interviews with patients and relatives so as to identify their problems and perceptions at an earlier stage. This health worker-patient-relative interaction and relationship can produce good results showed by the increase in living kidney donation, thereby cutting down cost on chronic renal failure management since renal transplantation is the best and most cost effective therapy of chronic renal failure.

5.4 LIMITATIONS OF THE STUDY

The researcher collected data using unstructured interviews and was able to utilise her skill and expertise regarding chronic renal failure and renal transplantation. The researcher's knowledge and expertise was utilised when she had to guide the participants on what to do and whom to contact regarding organ donation. Some of the participants found this threatening and were reluctant to express their feelings since they felt that their beloved relatives (patients) would be informed of their perceptions on organ donation irrespective of the researcher's effort of explaining the extent of confidentiality to them. This was the reason why they did not want to have their voices recorded. The researcher communicated this limitation to her supervisor who gave her permission to use only the field notes so as to make the participants comfortable.

The study was conducted in a selected public hospital in KwaZulu-Natal, Durban. Therefore the results cannot be generalised as there are three other public hospitals in the province where the relatives would also give some interesting results which may or may not support the findings of this study. It is acknowledged that the major disadvantage of non-probability sampling is that it does not contribute to generalisation, that the extent of the sampling error cannot be estimated and that bias may be present (Brink 2007:132).

5.5 CONCLUDING REMARKS

Successful kidney transplantation is associated with drastic improvements in survival and quality of life as well as considerable cost savings, compared with haemodialysis or peritoneal dialysis. This treatment modality of chronic renal failure can also result in greater ability of patients to participate productively in the community. The researcher

has met the objective of this study, which is to explore and describe the perceptions of the relatives of patients suffering from chronic renal failure regarding kidney donation.

Overall, global equity in donating the "gift of life" to those that are awaiting kidney transplantation will only be achieved through extensive public, patient and provider education, effective public policy, and continuous support from government and non-governmental organisations. As it has been identified by previous researchers, overall transplantation improves the lifestyle and life expectancy of the majority of patients with chronic renal failure, as compared to patients on haemodialysis and this is therefore challenging the fact that cohort studies need to be done and accurately reported. (Carpenter, Milford and Sayegh (2008:1668) argued that when the first degree donors are the relatives of the patient, graft survival rate per annum is 5-7% greater than those of cadaver grafts.

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Annexure A

Clearance certificate from the University of South Africa,
Health Studies Research and Ethics Committee

Annexure B

Questionnaire for data collection

Annexure C

Letter requesting permission to conduct research

Annexure D

Letters granting permission to conduct research

Annexure E

Informed consent form

Annexure F

Editor's declaration



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25 May 2011

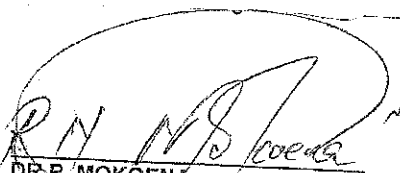
Principal Investigator:
➤ **Mrs P.N. Mbeje**

**PERMISSION TO CONDUCT RESEARCH AT ADDINGTON HOSPITAL:
"PERCEPTIONS OF THE RELATIVES OF PATIENTS SUFFERING FROM CHRONIC
RENAL FAILURE ABOUT DONATING KIDNEYS".**

I have pleasure in informing you that permission has been granted to you by Addington Management to conduct research on "Perceptions of the relatives of patients suffering from chronic renal failure about donating kidneys".

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Please ensure this office is informed before you commence your research.
4. Addington Hospital will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to Addington Hospital.



DR R. MOKOENA
HOSPITAL MANAGER

uMnyango Wezempilo . Departement van Gesondheid

Fighting Disease, Fighting Poverty, Giving Hope

Dr. RE Hodgson
Chairperson
Ethics committee
Addington hospital

25 May 2011

Dear Mrs. P.N Mbeje

**SUBMISSION TO ADDINGTON ETHICS COMMITTEE: PERCEPTIONS OF THE RELATIVES
OF PATIENTS SUFFERING FROM CHRONIC RENAL FAILURE ABOUT DONATING
KIDNEYS".**

Your submission has been considered by the Addington hospital Ethics committee. The project was deemed acceptable and may be carried out at Addington hospital

Please contact the committee should you require any further information.

Kind regards



DR. ERIC HODGSON

44 Avoca Hills Drive
Avoca Hills
Durban North
4051
17 May 2011

The Chief Executive Officer
Addington Hospital
P/Bag x 977
Durban
4000

Dear Dr Mokoena

Re-permission to conduct research study in your institution

I am a lecturer at Addington Nursing Campus and have registered with University of South Africa. I am currently doing a dissertation for Masters in Health Studies and my topic is: **"Perceptions of the relatives of patients suffering from chronic renal failure about donating kidneys"**. My supervisor is Dr. M.C Kriel and the joint supervisor is Dr. M.M Moleki.

I write this letter to ask for your permission to collect data at your institution. I have targeted Haemodialysis Unit as the field of my research study, where I will be interviewing the relatives of the patients with chronic renal failure who are brought for haemodialysis. I will cooperate with institutional policies and research ethics.

I intend commencing data collection on the **25th, 26th and 27th of May 2011**. The copy of Ethical Clearance Certificate from University of South Africa as well as the approved Research Proposal is attached.

I hope my request will receive your full and prompt consideration.

Yours sincerely

Mrs. P.N Mbeje

Signature: *P.N Mbeje* Lecturer

Contact details: Work: 031 3272818

Cell: 0825584707

E-mail: pretty.Mbeje@kznhealth.gov.za

UNIVERSITY OF SOUTH AFRICA
Health Studies Higher Degrees Committee
(HSHDC)
College of Human Sciences
ETHICAL CLEARANCE CERTIFICATE

Date of meeting: 15 April 2011

Project No: 3322-263-0

Project Title: Perceptions of the relatives of patients suffering from chronic renal failure about donating kidneys.

Researcher: Pretty Ntombithini Mbeje

Degree: Masters in Health Studies

Code: DIS702M

Supervisor: Dr MC Kriel

Qualification: D Litt et Phil

Joint Supervisor: Dr MM Moleki

DECISION OF COMMITTEE

Approved



Conditionally Approved




Prof E Potgieter
RESEARCH COORDINATOR


Prof MC Bezuidenhout
ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

ANNEXURE B

1	2
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PERCEPTION OF RELATIVES OF PATIENTS SUFFERING FROM CHRONIC RENAL FAILURE ABOUT KIDNEY DONATION**1. RESEARCH OBJECTIVES**

- To explore the perspectives of relatives of patients suffering from chronic renal failure about donating kidneys.
- To explore the reasons for and against kidney donations
- To make recommendations to family members about kidney donation.

2. ETHICAL CONSIDERATIONS

The informed consent is given voluntarily and confidentiality is going to be strictly maintained as your name only appears on the informed consent form where you've signed. A code is given on the on the interview guide instead of names.

Interview guide used by the researcher only after the participant has clearly understood the research objectives, ethical considerations and has signed the informed consent.

SECTION A: DEMOGRAPHIC DATA *(For official use only)*

1. What is your gender?

GENDER	ANSWER
Male	1
Female	2

3

2. What is your race?

RACE	ANSWER
African	1
Indian	2
Coloured	3
White	4

4

SECTION B: KNOWLEDGE AND PERCEPTIONS ON KIDNEY DONATION

3. Have you heard about chronic renal failure?

Yes	1
No	2

5

4. If the answer to the above question is “yes”, what is your understanding of chronic renal failure?

Not sure of chronic renal failure	1
Little knowledge of chronic renal failure	2
Good understanding of chronic renal failure	3

6

5. Explain how much important it is for your relative to come for haemodialysis as scheduled.

Does not understand the importance of haemodialysis	1
Understands the importance of haemodialysis	2

7

6. Have you ever heard about kidney donation?

Yes	1
No	2

8

7. If the answer to the above question is “yes” what are your perceptions about it?

Positive perceptions	1
Negative perceptions	2

9

8. How is organ donation, and especially kidney donation, viewed according to your own religion?

Positive perceptions	1
Negative perceptions	2

10

9. What health care did you initially seek when your relative started to have a kidney problem?

Taken to the nearest clinic or straight to the hospital or family doctor	1
Used over medication	2
Consulted the traditional healers or used herbal medication	3

11

SECTION C: GENERAL ASSESSMENT OF THE INTERVIEW BY THE RESEARCHER CONSIDERING ALL QUESTIONS ASKED.

10. Review of overall knowledge of chronic renal failure and kidney donation

Poor knowledge on chronic renal failure and kidney donation	1
Little knowledge on chronic renal failure and kidney donation	2
Good knowledge on chronic renal failure and kidney donation	3

12

ENGLISH CONSENT FORM

Informed Consent Form for Participants in Research Studies

**RESEARCH TOPIC: PERCEPTIONS OF THE RELATIVES OF PATIENTS
SUFFERING FROM CHRONIC RENAL FAILURE ABOUT DONATING KIDNEYS**

A. Participant's Statement

I, agree that I

- the research has been explained to me orally
- had the opportunity to ask questions and discuss the study;
- I understand that my participation will be tape recorded and transcribed
- I am aware of and consent to, your use of these recordings to achieve the objectives of your study.
- I understand that the interviews will be transcribed and used in publications but and that confidentiality and anonymity will be maintained.
- I understand that I am free to withdraw from the study without penalty if I so wish and I consent to the processing of my personal information for the purposes of this study only and that it will not be used for any other purpose.

Signed:

Date:

B. Researcher's Statement

I, confirm that I have carefully explained the purpose of the study to the participant.

Signed:

Date

Editing Declaration

P O Box 531
Hillcrest
3650
KwaZulu-Natal

2013-02-27

TO WHOM IT MAY CONCERN

Thesis Title: Perceptions of Relatives of Patients Suffering from Chronic Renal Failure About Kidney Donation

Author: Pretty Ntombithini Mbeje

This is to certify that I have edited the above thesis from an English language perspective and have made recommendations to the author regarding spelling, grammar, punctuation, structure and general presentation.

A marked-up version of the thesis has been sent to the author and is available as proof of editing.

I have had no input with regard to the technical content of the document and have no control over the final version of the thesis as it is the prerogative of the author to either accept or reject any recommendations I have made.

I accept no responsibility for the final assessment of the document

Yours faithfully

A handwritten signature in black ink, appearing to read 'M Addis', with a long horizontal stroke extending from the bottom right of the signature.

Margaret Addis